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ABSTRACT

This special supplement presents two background papers, three working papers, and key recommendations from a conference on culture and chronic illness in childhood. The meeting had as its goal the identification of the state of knowledge on the interface among culture, chronic illness, child development, and family functioning, for the purpose of developing "culturally appropriate" health policies, "culturally sensitive" services, and "culturally competent" clinicians. Comments by Robert R. Davila and Merle McPherson and a conference summary by Joan M. Patterson and Robert Wm. Blum precede the papers. The two background papers are: "Ethnocultural Variations in the Prevalence and Impact of Childhood Chronic Conditions" (Paul W. Newacheck et al.) and "Health Insurance Differentials among Minority Children with Chronic Conditions and the Role of Federal Agencies and Private Foundations in Improving Financial Access" (Margaret A. McManus and Paul Newacheck). The three working papers are: (1) "Multiculturalism, Chronic Illness, and Disability" (Nora Ellen Groce and Irving Kenneth Zola); (2) "Culture, Ethnicity, and Bicultural Competence: Implications for Children with Chronic Illness and Disability" (Geraldine Kearse Brookins); (3) "Culture, Ethnicity, and the Family: Critical Factors in Childhood Chronic Illnesses and Disabilities" (Hamilton I. McCubbin et al.). An annotated bibliography of 95 items (compiled by Gayle Geber and Elizabeth Latts) concludes the supplement. (DB)

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SUPPLEMENT TO PEDIATRICS

Culture and Chronic Illness: Raising Children With Disabling Conditions in a Culturally Diverse World

An Invitational Conference
Held at Wingspread
Racine, Wisconsin
June 1992

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Culture and Chronic Illness: Raising Children With Disabling Conditions in a Culturally Diverse World

An Invitational Conference
Held at Wingspread
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Sponsored by the Center for Children with Chronic Illness and Disability and the National Center for Youth with Disabilities, University of Minnesota; Department of Pediatrics, Division of General Pediatrics and Adolescent Health, University of Minnesota; the Institute for Disabilities Studies, University of Minnesota; Center for Family Studies, University of Wisconsin; and the Keland Endowment Fund of the Johnson Foundation.

This Conference was made possible through the generous support of: The Keland Endowment Fund of the Johnson Foundation and the Center for Family Studies, University of Wisconsin-Madison; Grant MCJ-2736 (National Center for Youth with Disabilities), Bureau of Maternal and Child Health and Resources Development, Department of Health and Human Services, and Grant H133B90012 (The Center for Children with Chronic Illness and Disability), National Institute on Disability and Rehabilitation Research, Department of Education, and Grant P30HD24051-04 (Institute for Disability Studies), National Institutes of Health.

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Introduction

In June 1992, 35 health care professionals, child and disability advocates, researchers, clinicians, and parents met at Wingspread Center in Racine, Wisconsin, for an invitational conference on Culture and Chronic Illness in Childhood. The meeting had as its goal the identification of the state of knowledge on the interface between culture, chronic illness, child development, and family functioning so as to lay the foundations for "culturally appropriate" health policy formulation, "culturally sensitive" services, and "culturally competent" clinicians.

The purpose of this special supplement is to establish a national agenda for research, policy, service delivery, and training in addressing the needs of all children with chronic illnesses and disabilities that takes the family, ethnicity, socioeconomic status, and culture into full account. To meet this task, five papers were commissioned. The first, by Newacheck et al, addresses the changes in incidence and prevalence of chronic illness and disability among children and youth by ethnic group. The second paper, by McManus et al, focuses on the trends in health services organization, delivery, and financing as they vary among ethnic groups in the United States. What emerges is a rhetoric of cultural sensitivity not paralleled in the organization or financing of health services.

Groce and Zola's paper addresses how cultural attitudes and beliefs are the foundations of our perceptions about health and illness. Those perceptions at times are predisposed to conflict with a health care professional who, coming from a different culture, may hold different norms and beliefs.

Brookins grounds her discussion within the context of child development and argues that for a child of color or one whose ethnic heritage is other than mainstream, the key to developmental success is bicultural competence—the ability to walk in and between two worlds. For those who have a disabling condition and are of an ethnic minority, there are perhaps three distinct cultures in which to function successfully.

As McCubbin et al note in their analysis of Native Hawaiians and Navajo, the family is key in mediating cultural norms, values, and beliefs of a community. Clearly, how families come to define a condition as a disability will greatly impact on their child-rearing practices, the messages of competence or handicap, and the values a child will come to see in him/herself.

The conference was not restricted to paper presentations; rather, the majority of time was spent in small-group discussions that focused on four general areas: culture and child development; the family as mediator of culture; and the organization of culturally sensitive or appropriate services.

The recommendations of the working groups are provided; they are divided into general recommendations and research, training, service delivery, and policy recommendations. One cannot have participated in the conference on culture and chronic illness or read the papers that comprise this special supplement without developing an appreciation of how limited our understanding is of culture and ethnicity and its impact on all aspects of the health, medical management, and well-being of children with chronic and disabling conditions. If we are really going to achieve the goal of assisting every child to reach his or her maximum potential, we must first begin to understand how the child's family, culture, and community define his or her competencies and limitations, establish norms of child rearing, and create expectations against which all children reared in the culture are measured.

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Introductory Comments

This conference comes at an appropriate time in our nation's history. As we move toward the close of the 20th century the full participation of individuals with disabilities in all aspects of daily life is gaining in importance. Never before have the needs, capabilites, and potential of people with disabilities received so much attention at all levels of government and in the private sector.

This increase in awareness and activity has brought with it the recogintion that the disability community, like society in general, is a diverse community, made up of people from many different backgrounds and walks of life. The needs of this community are as complex as the community itself; they are influenced by such factors as age, gender, disability, and of course, cultural background.

If we are to reach our goal of full participation for individuals with disabilities, our first task is to try to understand the various forces that shape the lives of individuals with disabilities in our society.

The Office of Special Education and Rehabilitative services (OSERS) supports the goal of full community integration for all persons with disabilities and their families. In our efforts to pursue this goal, we must consider the strengths and needs of children and their families from a variety of backgrounds. We must be aware of the unique ethnic and cultural values of children with disabilities and their families. These values give meaning to a particular illness or disability and affect current functioning and future developmental outcomes.

It is especially important for policy-makers and service providers to understand the differences that exist among people in a culturally divergent society. The material presented in these proceedings will go a long way in facilitating this effort.

Our country is recognized worldwide as a leader in including individuals from diverse backgrounds in the mainstream of American life. Children with disabilities and their families deserve no less.

Robert R. Davila, PhD
Office of Special Education and Rehabilitative Services
US Department of Education

Acknowledgments

The conference organizers wish first to acknowledge the generous support of the Johnson Foundation which supported all details of the conference at its magnificent facilities of Wingspread, a Frank Lloyd Wright masterpiece. A heartfelt "thank you" goes to Dick Kinch for his extraordinary attention to detail. Major support was provided for the conference through the National Institute on Disability and Rehabilitation Research, Center for Children with Chronic Illness and Disability as well as the Maternal and Child Health Bureau, National Center for Youth with Disabilities. The MCHB also provided the financial support which made this special supplement possible. Additional support was made possible through the cosponsorship of the University of Minnesota's Institute for Disabilities Studies. On a personal level, Harriet Kohen, Karen Stutelberg, and Annette Robles at the Center for Children with Chronic Illness and Disability attended to all aspects of the meeting which assured its success. And deep appreciation to Linda Boche who has revised, juggled, and organized manuscripts which have become this special supplement.

Finally, to all the participants who gave so generously of their time and knowledge over a weekend to assure the success of this meeting, thanks—you made it work!

Robert Wm. Blum, MD, PhD
Joan Patterson, PhD

General Comments

Merle McPherson, MD

As the year 2000 approaches, we as a nation face unique challenges in facilitating the development of systems of services for children and their families which support and nurture our next generation in healthy, productive lives.

Title V of the Social Security Act has a proud history of leadership in response to needs of children and families and has worked to improve the health of underserved women, infants, children, and youth, including children with special health care needs.

In 1989, amendments were enacted to the Title V Maternal and Child Health Grant (MCH block grant). These amendments redefine the mission of the state Children With Special Health Care Needs programs (CSHCN programs). The MCH block grant mandates the state CSHCN programs to assume a leadership role in developing community-based systems of services for children with special health care needs and their families.

The mandate in the MCH block grant to the CSHCN programs to assume a leadership role with respect to systems development reflects the national goal of building systems of services for children with special health care needs and their families that are family-centered, community-based, and coordinated. This goal was first enunciated in 1987 by the US Surgeon General's office and the federal Bureau of Maternal and Child Health. In accordance with this national goal, the recently issued Year 2000 National Health Promotion and Disease Prevention Objectives includes objective 17.20, which specifically calls for the building of family-centered, community-based, coordinated systems of services for this population.

The national initiative to develop systems of services for children with special health care needs and their families can and should be seen as part of a larger national movement to develop community-based systems of services. For example, part H of Public Law 99–457, enacted several years ago, has as its central thrust the development of family-centered, community-based, coordinated services, for a particular population—the birth to 3 population. A national initiative was also launched several years ago to develop systems of services for severely emotionally disturbed children. The federal Child and Adolescent Services System Program, known as CASSP, and the Robert Wood Johnson Foundation have been instrumental in promoting development of service delivery systems for this population. In addition, there is ongoing movement of national scope to develop coordinated systems of services for children and families involved with social services/child welfare and juvenile justice systems. This movement is receiving support from an increasing number of state legislatures and several national foundations.

The initiative to develop systems of services for children and families should thus be seen as a broad-based national movement to shift the paradigm to a family-centered philosophy and develop services and systems that recognize the pivotal role of families. This philosophy encourages agencies and professionals working together in partnership with families to build a community system of services which promotes family-centered, culturally-competent, coordinated care.

One of the greatest challenges to reaching our goal is the recognition of the increasing cultural diversity of our nation. We must respect and honor the families' unique racial, ethnic, cultural, and socioeconomic backgrounds. Cultural beliefs, practices, and attitudes toward illness and disability may vary widely, and programs and services must change to accommodate those beliefs, attitudes, and behavior. Moreover, the commitment to appropriately serve families of all cultural and socioeconomic groups by incorporating cross-cultural values must occur at the levels of policy, administration, practices, and advocacy in order to be effective. As the population of culturally diverse groups increases, health care providers must strive to understand the interface of culture, ethnicity, child development chronic disability and family systems. As this understanding and knowledge improves, we must adapt attitudes, policies, and practices which bridge the gaps in making services and systems relevant to divergent family cultural backgrounds.

On June 26 through 28, 1992, an invitational conference, Culture and Chronic Disease: Rearing Children in a Culturally Diverse World, was held at Wingspread in Racine, Wisconsin. The Center for Children With Chronic Illness and Disability sponsored the conference in collaboration with the National Center for Youth With Disabilities at the University of Minnesota and the Center for Family Studies at the University of Wisconsin. The purpose of this invitational conference was to convene several small, interdisciplinary working groups which included researchers, clinicians, program planners, policymakers, and parents to (1) review what is currently known concerning the impact of ethnicity and cultural norms and assumptions on how children grow and develop; and (2) establish a national agenda for research, policy, demonstration program-

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ming, and training in addressing ethnic and cultural issues relative to children with special health care needs and their families.

Two background papers were presented and four working papers were commissioned to serve as a stimulus for the working groups. The two background papers were presented by Paul Newacheck and Peggy McManus. These background papers examined the following two components: (1) trends in health care financing and service delivery and (2) the incidence and prevalence of chronic illness and disability by racial and ethnic groups for children aged 0 through 20.

The three working papers were written by the following people and addressed the following issues: (1) Dr Geraldine Brookins addressed the impact of culture on child development; (2) Dr Hamilton McCubbin examined the role of the family as the conveyor of culture; (3) Drs Nora Groce and Irving Zola addressed culturally sensitive services and chronic illness.

This special supplement consists of the two well-researched background papers, the three excellent working papers, and key recommendations from the conference. Fact sheets and press articles will be utilized in disseminating the recommendations to key audiences nationally.

We anticipate that this supplement will stimulate further discussion and response to the key recommendations, ultimately leading to improved services for all children with special health care needs and their families.

A Conference on Culture and Chronic Illness in Childhood: Conference Summary

Joan M. Patterson, PhD,*‡ and Robert Wm Blum, MD, PhD‡§

A focus on disability and chronic illness within the disciplines of health, education, and social services has usually assumed a dominant cultural ethos grounded in European-American values. Indicators of social and psychological competence, normative behavior, response to stress and to illness, and even adaptation to life have been assumed to comprise a relatively homogeneous pattern. "Abnormal" has usually been defined as deviation from this pattern. For the most part, there has been a failure to take into account the reality that there may be many different processes of adaptation utilized by different cultural and ethnic groups. Such adaptation patterns should not be viewed as deviant, but rather as different and comprising strengths, resources, and advantages, as well as potential problems and disadvantages. Unfortunately, the continuing prevalence of racism in our society has contributed to equating different with deviant.

Just as children from different cultural, ethnic, and racial groups are too often marginalized by society and experience restricted access or denial to important resources needed for optimal physical, psychological, and social development, so too, children who experience disability and chronic illness are too often marginalized by the attitudes and behaviors of others. The parallels between these two sources of exclusion—minority status and disability status—as well as the interaction of the two factors has received very little attention in research, service delivery, or policy formation.

Even though pluralism is inherent in the history of the United States, our orientation has been homogenization—"the great melting pot." This is changing. With awareness of the growing proportion of ethnic minorities comprising the US population and with a new positive value and emphasis being placed on ethnic diversity, there is renewed interest in cultural variation. Particularly, this has been observed in educational curricula where the dominant Eurocentric orientation in history and the social sciences has been challenged. Within the field of medicine, there is a new emphasis on minority health, growing out of the challenge from minority communities that limited research dollars have been spent to understand the health of ethnic populations in this country. This new emphasis has yet to extend to children and youth, however, who traditionally rank low in priorities for research funding and health and social programs. When we focus on the population of children and youth with special health care needs, we discover very little in the scientific literature about the prevalence and impact of chronic illness and disability among ethnic minorities.

The focus of the conference, Culture and Chronic Illness, Rearing Children in a Culturally Diverse World, was to examine what we know and, more importantly, what we need to learn, in three areas: the relationship between culture and child development; the role of the family in mediating culture; and the state of the service delivery system in responding to children with special needs from culturally diverse populations.

What follows are key recommendations that emerged from the conference—recommendations that focus on research, training, service delivery, and policy issues and that can inform future efforts to improve the quality of life of children with chronic illness and disability as well as their families.

GENERAL RECOMMENDATIONS

Include persons from diverse cultural and ethnic groups in all aspects of research, training, service delivery, and policy formation focused on children with chronic illnesses and disabilities. Given our professionalized systems of research and training, service delivery, and public policy formation, persons from diverse cultural backgrounds are frequently excluded. The rules, direction, and funding priorities become established at the "top" by those with more education and credentials, who often have little or no community-level or multicultural experience. This "top-down" model needs to be inverted so that the consumers of services have more direct input into decision making about the policies, programs, and services that directly affect them. This is particularly important when the groups to be served represent different cultures. A new "bottom-up" paradigm is needed, which calls for restructuring by whom and how decisions are made. Some federal agencies have taken the lead in mandating such grass-roots participation. For example, the National Institute on Disability and Rehabilitation Research requires evidence for "participatory action" in all proposals submitted to them. The Maternal and Child Health Bureau has recently called for science center proposals that require collaboration with community groups. It is presumptuous and arrogant for

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This summary was prepared with the assistance of the Workshop Recorders: Ann Garwick, PhD; Janet Titus, MA; and William Malcolm.

Anglo middle- and upper-class professionals to continue to believe and operate as though they know what is "best" for the underserved and disenfranchised in our society. The latter must be asked and included as active participants.

More understanding needs to be developed of distinct cultural groups and variations within ethnic groups rather than focusing on aggregated racial groups. One of the limitations of the present knowledge base about ethnic minorities is the tendency that has persisted of grouping many different cultural subgroups into one aggregate, such as black or Hispanic. Such grouping assumes a homogeneity that does not exist. Oversimplification has masked the rich diversity of cultures, has maintained a certain naiveté, and has contributed to negative stereotypes. For example, under the label "Hispanic," there are dozens of different cultural groups based on different countries of origin. These subcultures do not necessarily share common beliefs and practices about health or child rearing; neither do they respond to chronic childhood conditions in a common manner.

The approach to understanding and serving minority children with special needs should emphasize the resources and strengths inherent in diversity. Traditional models of research and service delivery have emphasized deficits. The search has been for what is wrong, pathological, or missing. This pejorative orientation tends to blind the investigator or the service provider to preferences, socialization patterns, and capabilities of different cultural groups.

How do children with special needs and their families from different cultures survive, adapt, and even thrive? There is a new emphasis in child development research focused on the concept of resilience, which seeks to identify those factors in the child, family, and community that contribute to good adaptation in spite of difficult circumstances.[1–3] This is the approach needed in the study of cultural diversity.

The emphasis on resilience and strengths should not be construed to mean that children and families do not need support from policies and programs; neither does it mean that they are *not* faced with special challenges. They are, and they need an extra margin of community support. Few families have the financial capabilities or physical and emotional tenacity to manage a chronic condition for a long period without outside resources and support. However, the support should build on the social structures that are already there, not replace or undermine them. Too often, when families only confront systems of care that view them pathologically, they start to believe they have no capabilities; they are disempowered. Rather, the goal should be one of empowerment, building on strengths and diversity, so as to increase a child's, family's, and cultural group's sense of worth.

The emphasis on the strengths inherent in cultural diversity should lead us to be more aware of the insidious presence of racism in our society and the many ways it undermines or denies the possibilities for children from minority groups to grow and develop and live a full, rich life of their choosing. Racism destroys both the victim and the perpetrator. It diminishes the whole of society but it disproportionately diminishes opportunity for the minority child, who must struggle to develop a positive identity in the face of discrimination (see Brookins, this issue).

There is need in research and in service delivery to adopt a broader definition of "family". In policy formation and service delivery, who is considered part of the family has a major impact on who gets served and how services are provided. Conventional definitions of "family" are not adequate to describe the diversity of family structures that exist both within and across cultural groups in the United States today. Who is "in" the family often extends beyond nuclear kin to include non-kin who function as part of a caretaking family. For example, among many African-American groups, close friends are considered "fictive kin" and fulfill the functions of family members.

One's family is not a constant entity. Over the course of time, individuals have membership in more than one family group, such as the family of birth and the marital family or family of association as an adult. The presence of chronic illness or disability has the potential to change the structure of the family. For example, one parent may leave if the burdens of a child's chronic illness become too great. Or, as has been observed with some stigmatizing illnesses such as acquired immunodeficiency syndrome, support from kin may be lost and a new caretaking family may emerge around the person who is ill.

More attention should be given to the way language is used in communicating with persons from diverse cultural groups. For communication and dialogue to occur, the meaning of the words used, the way they are said, and the nonverbal cues need to be shared, or at least understood. The barriers to communication when two different languages are spoken is obvious. However, even when the language is the same, the meaning can be very different. For example, in the disability field, the concept "independent living" is espoused as a goal. However, this phrase can be interpreted as living alone, which would be culturally unacceptable to some groups. Or, some families resent the phrase "family support," believing that it implies they are weak and need help. It is important to develop shared meanings, especially when working with people from different cultural groups. In all instances, effort should be made to make words and language genuine, and not simply buzz words or professional jargon that has been developed for the convenience of different disciplines.

RESEARCH RECOMMENDATIONS

Expand the number of studies that examine the development and adaptation of children with chronic illness and disability from diverse cultural and ethnic groups. Most research has focused on the development of children from different cultural backgrounds or on the impact of chronic illness or disability on development, but few studies have examined the interrelationship between different cultural groups and chronic conditions. There has been a tendency to focus on exotic cultural practices, contributing to stereotypes, rather

than examining cross-cultural beliefs related to disability, illness, health practices, and child rearing. Studies are needed that distinguish that which is different from that which is detrimental to health.

Adaptation to chronic illness and disability is an ongoing process for children and for their families. Thus, studies of adaptation need to focus on process as well as outcomes. The reciprocal impacts between the child's condition and the functioning and response of the social context of family and culture are dynamic and call for methods that capture interactive process as well as change over time. A child's chronic illness has a critical impact on his or her development. Longitudinal studies that follow children and their families over a period of time are needed to adequately describe the multiple interactions and transactions that occur between illness, child development, family functioning, and community response. Examining process and transactions will lead to greater understanding of the mechanisms of risk and the mechanisms of resiliency in different cultural groups.

In many studies, there has been a tendency to aggregate many cultural subgroups, who often are very different, into one conglomerate such as Hispanic or black. For research questions focused on understanding and then promoting development and competence in children from different cultural groups, the strategies need to be different. Multiple studies with smaller samples need to be done, using methods and statistics appropriate for small sample sizes.

More qualitative research should be undertaken so that a comprehensive understanding of diverse cultural patterns in response to chronic illness and disability in children can be developed. It would be misleading and a distortion of cultural diversity to simply impose existing strategies and instruments, which primarily have been developed on Anglo-American populations, by Anglo researchers, to the study of children with chronic conditions from different cultures. Given the current, limited knowledge about ethnically diverse children with special health care needs, it is essential that we build this knowledge base inductively and use grounded approaches to develop our understanding. The cultural meanings of chronic illness and disability, as well as the meanings of child competence, health, and well-being, are critical to understanding the adaptation of families with children with special health needs. It is only with qualitative methods that this subjectivity can be described.

Funding agencies traditionally have given more support to research that is deductive, hypothesis-driven, and produces quantitative results. Funding agencies should be encouraged to support qualitative research as well. Quantitative and qualitative methods actually complement each other, and these findings are needed to shape public policy and to inform the development of more responsive service delivery systems.

The prevalence of chronic illness and disability among children from different racial and ethnic groups needs to be determined. Our present national health surveys do not provide sufficient information about the health status of children from diverse ethnic groups; nor is information about the presence of chronic illness and disability in children adequate to formulate health policy or plan programs. More attention needs to be given to the sampling procedures in these surveys so that adequate numbers of children from diverse ethnic groups are included (oversampled) so reliable estimates of prevalence can be generated.

Reliable and valid research instruments for studying children with special needs from different racial and ethnic groups need to be developed. It is acknowledged that many research questions can best be answered using quantitative methods and standardized protocols. However, many of the standardized questionnaires for assessing child and family functioning have been developed and normed primarily on Anglo children. When used with minority groups, the results are seriously misleading and offer a distorted and inadequate basis for developing programs or formulating policies.

More studies are needed that identify the components of culturally competent service delivery. With the resurgent interest in cultural diversity, there has been a renewed interest in and call for culturally competent service providers. However, we lack understanding of what constitutes culturally competent service provision as different from generic competence. A key to studying this and understanding it is to focus on process. However, process research has received limited support from funding agencies. Reductionistic, linear approaches with clearly defined outcomes have been viewed as more valuable in searching for cures for disease. There is, however, growing interest and attention focused on quality of life, rather than on just life itself, as an outcome. Patients with chronic illness and disability and their family members have attested that the process of getting health care services to attain health and quality of life is as important, if not more important, than the outcome. When surveys of patient satisfaction with services are coupled with the vast literature on noncompliance with prescribed medical regimens, it would suggest that more effort needs to be placed on the dynamic interactions that occur between patient and provider in service delivery settings. Nowhere is this need more apparent than when children and families of different cultural and ethnic backgrounds (than the service provider) enter the health care system.

Expanded research is needed to determine the components of family-centered, community-based service delivery systems that are responsive to the needs of culturally diverse families who have children with special health care needs. The process of adapting to life involves discovering how to meet one's needs in one's sociocultural context.[4] Presumably, there are levels of adaptation, from surviving, at one extreme, to thriving, at the other. In other words, there is a range of the "goodness of fit" between the child and family and their social context.[5]

Most professionals, working with children with disabilities and their families, are trying to create the context for adaptation and in so doing, make a priori assumptions about what the needs are. Resources are

developed and programs are planned to meet them. Following the newer mandates for family-centered, community-based care for children with special health care needs,[6] professionals assess which of the needs the child and the family has and then they are more or less "fit" into these categorical resources and programs. However, for many families, especially from minority cultures, the resource and program options may not fit their perceived needs at all. There is a need to reverse the process and identify the needs first and then develop the resource programs.

In addition to this kind of more grounded family-needs assessment, there are several aspects of community-based service that need to be systematically examined:

- What level of training is needed by service providers to provide effective, culturally competent services? For example, are paraprofessionals of the same cultural group as persons served more (or less) effective than professionals with more training, who cost more, and often are from a different cultural group?
- Where should services be provided? Most often services for children with special needs have been provided in specialized clinics, often remote and foreign to immigrant families and to persons of a different culture and social class. Results of the pediatric ambulatory care trial[7] are one example of how changing the site of service delivery had a positive impact on child and maternal health outcomes. Additional studies that systematically vary the location of services, especially for minority groups, are needed.
- Studies need to be done to determine whether a provider can be culturally competent if from a culture other than the one of the person who is served.

RECOMMENDATIONS FOR TRAINING

Training programs should be developed that prepare service providers to be culturally competent and empower families. Most health professionals, and to a lesser extent, education and social service professionals, have not been adequately trained in the skills needed to provide service that is both culturally sensitive and that empowers recipients. For the most part, existing service providers and training faculty received their education before the current emphasis on and valuing of cultural diversity. Thus training curricula and models of training that take diversity into account need to be developed, tested, and evaluated. Specific components that should be addressed in such training curricula include the following:

- Self-awareness and attitudes of the trainee should be assessed early in training and the capacity for greater sensitivity to and respect for diversity should be developed. Documentation of this capacity should be a requirement for certification for all health care professionals.
- Communication-skill training should emphasize the ability to listen, to integrate the affective level of a message with the words spoken, to develop shared meanings for words and phrases not understood by all persons in the dialogue, and most importantly, the ability to take and articulate the perspective of the other.
- Skills should be developed for assessing cultural practices that are relevant to the child's health, such as beliefs and practices related to child rearing or the care and treatment of chronic illnesses.
- Skills for empowering families should be taught. This requires movement away from the traditional medical model of identifying what is wrong, to the ability to facilitate families' capabilities to identify their own needs and strengths, to develop new abilities, and to learn how to effectively access other resources in their communities.
- Skills need to be developed in recognizing and resolving conflicts that emerge between standards of care usually grounded in a Western medical model and cultural practices. The ability to identify and work effectively with recognized leaders in a cultural community may facilitate this kind of conflict resolution.
- A greater portion of training should take place in community settings. Experiential learning should be incorporated into the training of health, education, and social service practitioners so they actually spend time and interact with patients and clients on their turf—home, school, workplace, neighborhood, and any other social contexts where the patient/client/family spends time.

Increase the number of minority trainees in all disciplines. Health care professionals as well as other service providers from diverse cultural backgrounds are needed in service delivery systems. We need to move beyond traditional affirmative action programs and actively recruit for diversity. Support for minority students needs to begin at the junior and senior high school levels. Financial barriers often keep qualified students from pursuing professional careers. Thus, increased scholarship funds are needed for minority students who are interested in health, education, and social service careers.

Increase the number of minority faculty in training programs. Minorities are underrepresented or absent among most health and education faculty. Here, too, we need to move beyond traditional affirmative action plans and actively recruit for diversity. In addition to serving as role models, the presence of minority faculty increases the probability that all curricula will place greater emphasis on diversity issues.

SERVICE DELIVERY RECOMMENDATIONS

Increase access to services for minority children with chronic illness and disability. National survey data indicate that minority children with disabilities are seriously underserved by the present health care delivery system (see McManus, this issue). Liaisons between the community and health care agencies need to be fostered. There needs to be greater financial support for community outreach workers who know how to disseminate information in a given community. Ethnic and minority leaders need to be educated and encouraged to advocate for services on behalf of children with special needs.

Increase demonstration projects that develop and evaluate innovative models for delivering health care and other services to minority communities. Professional guilds play a major role in developing uniform standards of care and mandated levels of services. However, these standards, set by professionals, may not be relevant to the needs of diverse communities. Thus, it is important that demonstration projects include underserved, disenfranchised persons as part of the health care planning team. Primary care models of health care delivery need to be reexamined, since they are often based on inadequate data. Service models that are better coordinated, comprehensive, continuous, and flexible for a given cultural community needed to be studied more carefully. Outcome goals need to be identified within a community-based structure. All demonstration projects need to include strong evaluation components that document effectiveness.

Providers of service need to be accountable to the persons they serve. Providers of care are usually most accountable to the administrative hierarchy, to the source of funding for services. However, providers and the whole system in which they work need to be equally accountable to consumers. The principles of total quality management need to be applied to all customer groups, including ethnic and cultural minorities. Mechanisms for getting consumer input and feedback, such as hot lines, focus groups, and toll-free telephone numbers for voicing concerns, need to be developed and tested.

POLICY RECOMMENDATIONS

A comprehensive national financing system for children's health care needs to be developed. The current health care system consists of a patchwork of categorical programs that leave many children without needed health care services. New models of child health care that unify financing and delivery in the same system need to be developed and tested. These models need to be equitable, comprehensive, and culturally sensitive. Federal standards should be written with a core of minimum requirements so that differences in health care needs at the state and local levels can be taken into account. This is particularly important if health care services are going to be responsive to the needs of different cultural and ethnic groups.

The Year 2000 National Public Health Objectives need to be evaluated and restated so they include the health needs of children with chronic illness and disability and the health needs of different cultural groups. The Year 2000 Objectives are based primarily on mortality statistics rather than community needs. As currently articulated, they inadequately address the needs of children with special needs. Health objectives for culturally diverse populations need to be reexamined in coordination with the Office of Minority Health.

CONCLUSION

We are currently in the midst of a paradigm shift, or perhaps multiple shifts, regarding our understanding and notions of disability, of health services, of family, and of culture. At the core of the paradigm are central cultural values. As one conference participant noted, ours is a society driven by an abiding belief that *liberty* is the highest value. In contrast, the fundamental ethos in Canada is one of *fairness*. Perhaps, within the liberty paradigm, independence has been the central goal of child development. However, if we were to shift to a fairness paradigm, reciprocity would be the process and the outcome goal would become interdependence.

Interdependence is how we engage among and between ourselves, whether as a family or as a community. It implies commitment, both interpersonally and transactionally. Some of the conferees articulated a need for a "Child Bill of Rights" as a framework within which children could grow and develop. Such does not exist today in the United States. We are a long way from having agreement about healthy child development and about our mutual responsibility to assist *all* children in achieving that goal. We do not as yet view children as a collective responsibility. As a consequence, we define special categories to identify those who are worthy—"disabled," "mentally retarded," "children with special health care needs," and so on.

Throughout the conference, it became clear that social competence for those who by birth or by acquired disability are out of the mainstream involves *biculturalism*. Biculturalism is apparent and contributes to better adaptation on many different levels: ethnic cultures vs mainstream culture, male vs female culture, upper class vs lower class, and persons with disabilities vs those with no disabling condition. However, cross-cutting all of these and other social differences that exist and should be welcomed is the experience of racism, sexism, and handicappism, which denigrate the individual for deviating from the mainstream. One cannot talk about enhancing social competence among those with physical differences without giving them some training in how to confront "isms." Whether you are a white kid who grows up using a wheelchair, whether you are an African-American kid who grows up out of a wheelchair, whether you are a Hispanic kid who lives in poverty, if you are different in some way, you will likely experience discriminatory treatment. As clinicians, it is critical that we be aware of the impact of racism and other "isms" on the lives of those who are out of the mainstream. As educators, we need to help children to be more competent in dealing with what we know should not exist but does. As human beings, we need to examine our own attitudes and behaviors, to be personally vulnerable in examining our own limitations, and to develop our skills and enhance our competence for working and living in a diverse society.

As Groce and Zola (in this issue) have pointed out, the metaphor of the United States as "the great melting pot" fails to meet the needs of those who do not blend. Perhaps a better image is what Margaret Spencer[8] has referred to as "chunky stew," where both differences and social integration are acknowledged, valued, and *celebrated*.

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Ethnocultural Variations in the Prevalence and Impact of Childhood Chronic Conditions

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ABBREVIATIONS. NHIS, National Health Interview Survey; NHIS-CH, NHIS on Child Health; NCHS, National Center for Health Statistics; AAP, American Academy of Pediatrics.

Chronic physical and mental illnesses are an important contributor to childhood morbidity. National survey data indicate that childhood chronic illnesses result in more than 35 million bed days and 40 million school absence days annually.[1] There is also evidence to suggest that the burden of chronic illness is growing for children.[2–4] Specifically, advances in diagnosis and treatment have dramatically changed mortality rates for children with chronic conditions, with the result that many children with life-threatening chronic conditions now survive into adulthood.[5,6] In addition, a new class of childhood conditions, often referred to as the "new morbidities," has emerged in recent years.[4,7]

Despite concern about the welfare of this population, relatively little is known about the prevalence of childhood chronic conditions or their impact, especially for minority youth. Past studies have often categorized minority populations into the general and nonspecific category of "nonwhite." Alternatively, some studies have reported results only for white and black children; hence published information is particularly sparse on chronic illness among Hispanic, Asian, and Native American children.

Previous studies that have examined racial and ethnic variations in the prevalence of childhood chronic conditions can be divided into those that are based on household interviews, those based on medical records, and those based on birth-defects–monitoring systems. The results for some of the larger studies are summarized in Table 1. Excluded from this table are disease-specific studies.

Only a few household interview studies have reported results concerning racial and ethnic differences in prevalence of chronic conditions. One of the earliest household interview studies to explore racial differences derived data from a survey of parents in Alamance County, North Carolina.[8] In this study of 13 categories of chronic childhood disorders, the authors found higher rates among blacks as compared with whites for most of the conditions studied. In their interviews with parents of 3072 children in Genessee County, Michigan, Walker and her colleagues[9] found the reverse pattern. In their analysis, whites had higher reported prevalence rates than blacks for most of the chronic conditions studied, although the differences were statistically significant only for speech disorders and bronchitis.[9] A more recent analysis of population-based data from the 1981 National Health Interview Survey on Child Health demonstrated essentially no difference in aggregate prevalence between blacks and whites (91/1000 vs 89/1000) for 19 chronic conditions.[10] Another large-scale study of chronic conditions severe enough to cause limitations in school activities reported prevalence rates of 40 per 1000 for white non-Hispanics, 37 per 1000 for black non-Hispanics, and 34 per 1000 for Hispanics.[11] This study also demonstrated differences in the rates of inability to attend school (the most severe activity limitation measured), with a rate of 3 per 1000 among white non-Hispanics, 5 per 1000 among black non-Hispanics, and more than 7 per 1000 among Hispanics.

Studies of medical records and clinician impressions reveal a pattern of higher prevalence among minority children. In their large survey of medical records in Erie County, New York, Sulz and his colleagues[12] reported prevalence rates higher among nonwhites than whites for 10 of 15 chronic conditions. But because these data were based on inpatient hospital records, the reported prevalence rates might have reflected a detection bias favoring nonwhites, given the inverse relationship between income and inpatient utilization reported by the authors.[12] Using clinic-based data derived from a survey of physicians in Monroe County, New York, during 1979 Weiland and colleagues[13] recently reported aggregate prevalence rates (based on 10 058 children) of 204 per 1000 for nonwhites as compared with only 152 per 1000 for whites for quite broadly defined chronic physical disorders.[13]

Prevalence data from birth-defects–monitoring systems show small prevalence differences between whites and blacks, but larger differences between whites and Hispanics. The most comprehensive data on race-specific rates of congenital malformations (many of which result in chronic conditions during childhood) come from the Birth Defects Monitoring Program administered by the Centers for Disease Control. This database, encompassing records for more than 4 million livebirths between 1981 and 1986, demonstrated an aggregate incidence rate of 18.9 per 1000 among whites as compared with 17.9 per 1000 among blacks and 14.4 per 1000 among Hispanics for 18 congenital malformations.[14]

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TABLE 1. Previous Studies on Childhood Chronic Disease Prevalence

Study (Year)	Design and Sample	Findings	Conditions Examined
Richardson and Higgins[8] (1965)	Alamance County, NC Parental report; 5% random household survey plus agency reports plus clinical validation N = 1684, persons age 0–21	Aggregate prevalence 162/1000; black > white for 8/14 conditions	Orthopedic conditions, epilepsy, hearing, vision and speech disorders, respiratory disorders, heart conditions, cerebral palsy, skin conditions, cleft lip or palate, mental retardation, orthodontic conditions, emotional disturbance
Sulz et al[12] (1972)	Erie County, NY Multiple clinical records (largely inpatient hospital records) N = 337 275 county population, age 0–16 N = 3422 identified hospitalized cases	Aggregate prevalence approx 13.1/1000 based on inpatient data; white > "nonwhite" for 5/15 conditions; "nonwhite" > white for 10/15 conditions	Cystic fibrosis, diabetes mellitus, hemophilia, peptic ulcer, ulcerative colitis, asthma, nephrotic syndrome, thalassemia, sickle cell disease, cirrhosis, systemic lupus erythematosus, adrenal disease, eczema, hypothyroidism, histiocytosis X
Erickson[24] (1976)	Congenital Malformation Surveillance Program, CDC* Hospital records from metropolitan Atlanta N = 2255 affected live births	Incidence rates (at birth) markedly higher for whites vs blacks for 7/8 individual (single) anomalies; rates equal for multiple anomalies	Anencephaly, spina bifida, trachceoesophageal fistula, hypospadius, cleft lip, cleft palate, club foot, polydactyly
Walker et al[9] (1981)	Genessee County, MI Parental report, household survey N = 3072, age 0–17	No aggregate prevalence data provided White > black for most conditions	Asthma, hayfever, allergy, kidney disease, heart condition, hearing, vision and speech disorders, missing extremities, deformities, congenital malformation, paralysis, mental impairments, arthritis, bronchitis, epilepsy, cerebral palsy, diabetes
Myrianthopoulos[25] (1985)	Collaborative Perinatal Project Hospital (birth) records Children with congenital malformations followed for 7 y	At 7 y: black approx = white for major malformations; black > white overall (aggregate) due mostly to higher frequencies of a few minor malformations; white > black for multiple malformations	16 major and 23 minor congenital malformations
Chavez et al[14] (1988)	Birth Defects Monitoring Program, CDC Hospital (birth) records from 1500 US hospitals covering 4 617 613 live births	White 18.9/1000 > black 17.9/1000 > Hispanic 14.4/1000 (incidence at birth)	Anencephaly, spina bifida, hydrocephalus, microcephaly, congenital heart disease, cleft lip, cleft palate, club foot, hip dislocation, hypospadius, rectal atresia, fetal alcohol syndrome, Down syndrome, other autosomal abnormalities
Gortmaker et al[10] (1990)	1981 National Health Interview Survey Parental report N = 11 699 children age 4–17 y	Aggregate prevalence 89/1000; black slightly > white (91/1000 vs 89/1000)	Arthritis, asthma, blindness, vision impairment, cancer, heart disease, cerebral palsy, cystic fibrosis, deafness, deformity, diabetes, cleft lip/palate, epilepsy, chronic digestive (colitis, ulcer), hearing impairment, missing limb, orthopedic problem, paralysis, sickle cell disease
Weiland et al[13] (1992)	Monroe County, NY Physician Survey N = 10 058 children (county population) N = 1573 children with chronic illness Age 4–16 y	Aggregate prevalence 156/1000; nonwhite > white (204/1000 vs 152/1000)	"Serious" disorders of the following organ systems: endocrine, hematologic, neurologic, sensory, circulatory, respiratory, digestive, genitourinary, dermatologic, musculoskeletal; also hayfever dermatitis, speech/language disorders
Trevino[11] (1984)	1978–1980 National Health Interview Survey Parental report, household survey N = 58 346, age 0–17	Aggregate prevalence of activity limitation due to chronic conditions 39/1000; white 40/1000; black 37/1000; Hispanic 34/1000	Limitation of activity due to chronic conditions (specific conditions not specified)

* Centers for Disease Control.

Findings from the studies reviewed here are not altogether consistent. Some suggest that chronic conditions are more prevalent among minorities, others suggest the reverse, and still others suggest that no differences exist across racial and ethnic groups. This variability is likely to be at least partially attributable to variability in the definition of childhood chronic illness. Researchers have been far from consistent in the selection of specific chronic conditions included in epidemiologic studies, and no consistent list of specific chronic disorders has emerged in the research literature. The epidemiology of chronic illness in childhood is characterized by very few disorders that are common, and by a large number that are quite rare.[15] Decisions concerning which of the many uncommon chronic disorders to include have been far from consistent. Further, it is likely that variation in reported prevalence rates also has resulted from different methodologic approaches used in data collection. As a result, it is impossible to make definitive

conclusions concerning prevalence for the different racial and ethnic groups from existing studies.

The present study provides estimates of the prevalence of chronic conditions in children of different racial and ethnic heritage from the 1988 National Health Interview Survey on Child Health (NHIS-CH). Using this survey to derive prevalence estimates offers a number of advantages over some of the previous studies. First, the use of a population-based sample provides for more representative results than can be obtained from sampling patients appearing at clinics, hospitals, or other treatment centers. Second, the use of a nationally representative sample eliminates geographic biases that might result from localized, small-area samples. Third, the large sample size (N = 17 110) permits more precise prevalence estimates than could be obtained from smaller samples. Finally, the NHIS-CH is the most current population-based survey available for estimating prevalence of childhood chronic conditions.

Data from the survey are used in this paper to examine the prevalence and impact of childhood chronic illness according to race and ethnicity. We present aggregate prevalence estimates and individual prevalence estimates for 19 different categories of primarily physical chronic conditions. We describe how prevalence varies when other measures of sociodemographic status, such as family income, are taken into account. We examine the impact of chronic conditions on children's activity levels and show how childhood chronic conditions influence utilization of health services. All of these analyses are conducted for three different racial and ethnic groups of children: white non-Hispanic children, black non-Hispanic children, and Hispanic children. We focus particular attention on whether access barriers exist for black and Hispanic children with chronic illness relative to their white peers.

METHODS

The National Health Interview Survey (NHIS) is a continuing nationwide survey, conducted by the Bureau of the Census for the National Center for Health Statistics (NCHS). The purpose of the survey is to collect information on the health status and use of health care by the US population. The sample is designed to be representative of the US civilian noninstitutional population.[16]

In 1988, a special supplemental questionnaire on child health was included in the survey. The questionnaire, similar to one used in 1981, covered a range of topics relevant to child health including child care, pregnancy and birth, behavioral problems, developmental problems, other child health problems, and use of health services. One child in each household was selected at random to be the subject of the supplemental interview. An adult member of the household knowledgeable about the child's health served as the respondent. In about 90% of the cases the respondent was a parent of the sample child, usually the mother. Interviews were completed for 91% of all eligible children, resulting in a sample of 17 110 children younger than 18 years old.[16]

For purposes of this analysis, the sample was divided into three groups based on racial and ethnic background. It should be noted that the racial and ethnic identity of the respondents in this survey is established by way of self-reporting. The sample was first divided into white, black, and other races. The "other" category included Asians/Pacific Islanders; Aleut, Eskimo, or American Indian; "multiple races"; and other racial minorities. None of these subgroups was large enough to permit calculation of statistically reliable estimates, and the larger category was considered too heterogeneous to permit meaningful analysis. Children in the "other" racial category were then excluded from the racial and ethnic comparisons. The remaining sample children were subdivided into three groups based on their race and ethnicity: white but not of Hispanic origin (n = 12 097); black non-Hispanic (n = 2859); and Hispanic (n = 1664). In the presentation that follows, these groups are simply referred to as white, black, and Hispanic.

Determination of the prevalence of chronic conditions was made possible by the inclusion of a detailed checklist of childhood health conditions in the supplement. The checklist was oriented toward recurrent or chronic conditions. Respondents were read this extensive list and asked whether the sample child had any of the included conditions during the previous 12 months. Using these results, annual prevalence estimates can be derived for a variety of childhood health problems as diverse as repeated ear infections, cerebral palsy, and juvenile arthritis—but excluding minor acute illnesses, such as colds and the "flu." In part because of past problems of underreporting, cancers and mental health problems without physical manifestations were excluded from the checklist.

Eight pediatricians, primarily for university medical centers, were impaneled to review the 76 checklist conditions to determine whether any should be excluded from our analysis of chronic conditions. Where a majority considered a condition not to be chronic, it was eliminated. A total of 8 conditions were eliminated in this fashion. The remaining conditions were classified according to chronicity using conventions similar to those developed by the Division of Health Interview Statistics of the NCHS. Specifically, a condition was considered chronic if (1) the respondent indicated it was first noticed more than 3 months before the interview date, or (2) it was a type of condition that ordinarily has a duration of more than 3 months.[16] Examples of conditions that are considered chronic regardless of their time of onset include diabetes, heart conditions, and arthritis. A complete list of these conditions is included in Appendix 1. Because no severity criteria . re used, this approach to defining chronic illness leads to inclusion of a large number of conditions, including some of the so-called "new morbidities." As such, this definition provides an upper bound estimate of the size of the child population with physical chronic conditions.

To enable a manageable analysis and presentation, conditions were grouped into 19 broader impairment and disease groupings. The categorization scheme is based on grouping conditions that are related in a clinical fashion while taking into account constraints due to sample-size limitations. The overall categorization scheme and condition groupings are illustrated in Appendix 1.

Data on the impact of checklist conditions were also collected in the supplement. Each time a condition was reported as present during the past year, a set of follow-up questions was asked about the frequency and amount of bother caused by the condition, and the use of medications, physician services, and inpatient hospital care that resulted from that condition. Together, these data permit analysis of the impact of chronic conditions on children's health status and health care utilization patterns. The questions and probes used in this analysis to identify the impact of chronic conditions are reproduced in Appendix 2.

A follow-up question on limitation in play and sports activities was included in the supplement, but the question was asked only for children with selected chronic conditions. However, the core questionnaire contained questions on limitation of activity due to chronic conditions that were asked for all children. Results from these questions were used to determine whether sample children were limited in age-appropriate activities, such as school or play.

We examined access to health care by determining whether children had usual sources of care for routine care and sick care. Information on usual sources of medical care for sample children was collected using two different sets of interview questions. The first set of questions concerned visits for routine care needs and the second concerned places for obtaining care when the child was sick. Routine care was defined as "including routine checkups and immunizations when nothing was wrong." Sick care was defined to include "health care when (name) is sick or injured." Using results from these questions we classified children according to whether or not they had a usual source of routine or sick care.

The results are weighted to reflect national population estimates. The reader should note that prevalence estimates for individual conditions can be unreliable due to sample-size limitations. To assist the reader in identifying potentially unreliable prevalence results, we have noted those prevalence estimates with relative standard errors in excess of 30% by an asterisk in Table 4. Caution should be exercised in interpreting such estimates. Standard errors

were calculated using either formulae provided by the NCHS or software designed to take into account the complex sample design of the NHIS.[17,18]

RESULTS

Aggregate Prevalence of Childhood Chronic Conditions

As shown in Table 2, an estimated 31% of children younger than 18 years old, or almost 20 million nationwide, were reported to have one or more chronic conditions in 1988. The reader should remember that this estimate pertains to the prevalence of chronic conditions regardless of whether they result in restriction or need for medical care. Even so, it is likely that these estimates understate the true size of the child population with chronic conditions, since not all chronic conditions—particularly those related to mental health—were included in the checklist.

Large differences are apparent in the reported prevalence of chronic conditions among the three racial and ethnic groups. Families of white children were much more likely to report chronic conditions for their children (336/1000) than were families of black children (246/1000) or families of Hispanic children (242/1000). Hence, white children were 37% more likely than their black peers ($P < .01$) and 39% more likely than their Hispanic peers ($P < .01$) to be reported as having one or more chronic conditions in 1988.

It is possible that these racial and ethnic prevalence differences could be attributable to other confounding variables, such as income or access to health care. That is, it is not clear to what extent the results described above reflect underlying racial and ethnic differences or differences in other variables that are correlated with race and ethnicity. We investigated this possibility by performing a hierarchial multiple regression analysis (Table 3). In the first step we simply included variables indicating race and ethnicity as predictors of whether the sample child had one or more chronic conditions. In subsequent steps we added variables reflecting age, gender, region of residence, population density, family income, and maternal education. In the final stage, we added two measures of access to health services: insurance coverage and presence of a usual source for routine health care. If these variables account for some or all of the racial and ethnic effects seen in Table 2, then the regression coefficients for the race and ethnicity variables should decrease in magnitude as the other variables are added to equation. However, this was generally not the case as can be seen in Table 3. We did find a slight diminution of effect for the Hispanic origin variable, indicating that a very small component of the prevalence difference between whites and Hispanics shown in Table 2 is attributable to confounding (specifically, due to the socioeconomic and access variables). However, virtually no change occurred in the coefficient representing black children as other potentially confounding variables were added to the model. Hence, none of the prevalence differential between whites and blacks and very little of the prevalence differential for Hispanics and whites shown in Table 2 appears to be attributable to confounding by age, gender, residence, income, education, or access to care.

TABLE 2. Prevalence of Chronic Conditions Among Children Younger Than 18 Years: United States, 1988*

	Cases/1000	Cases in 1000s
All children†	307.6	19 556
White	335.9	14 995
Black	245.9	2 346
Hispanic	241.8	1 750

* Source: original tabulations of the 1988 National Health Interview Survey.
† Includes white, black, Hispanic, and other races.

Prevalence Estimates for Individual Chronic Conditions

As shown in Table 4, the most commonly reported childhood chronic conditions included respiratory allergies (hay fever and other respiratory allergies) and frequent or repeated ear infections. Respiratory allergies affected 10% of children while 8% of children experienced repeated ear infections. Other relatively common conditions included asthma, eczema and skin allergies, frequent or severe headaches, and speech defects. Each of these had a prevalence of 25 per 1000 or more. Conditions of low prevalence included diabetes, sickle cell disease, and cerebral palsy. Each of these conditions affected fewer than two of every thousand children in the United States.

Prevalence rates varied considerably among white, black, and Hispanic children. While white children demonstrated considerably higher aggregate prevalence for the sum of all conditions examined, much of this difference is explained by a small number of common (and perhaps associated) clinical conditions. White children were seen to have considerably higher rates of allergy-related chronic conditions such as hayfever/respiratory allergies, food allergies, and eczema/skin allergies. These conditions, in combination with chronic middle ear infections, can represent the clinical spectrum of the atopic syndrome (or allergic phenomena) and together account for much of the overall higher chronic illness burden reported for white children in our sample.

Uneven Burden of Childhood Chronic Illness

The condition-specific results suggest that the higher overall prevalence of chronic conditions among white children may be attributable to more frequent reporting of common but clinically minor conditions that also may impact children only mildly. We examined this possibility by assessing how often chronic conditions bothered children and whether they were associated with limitations in school or play activities. Using these indicators we divided children with chronic conditions into three severity categories: mild, moderate, and severe. Children were classified as having mild conditions if they experienced only occasional bother or no bother and had no limitations in their usual activities. The moderate group was composed of children with conditions that resulted in more than occasional bother or limitation of activity, but not both. The severe category consisted of children whose conditions caused more than occasional bother and who experienced limitation in their activities.

TABLE 3. Regression Results for Prevalence Equations*

Independent Variables	Equation			
	I	II	III	IV
Intercept	.345‡	.313‡	.189‡	.091†
Black	−.087‡	−.087‡	−.083‡	−.083‡
Hispanic	−.088‡	−.090‡	−.069‡	−.063‡
Age (y)		.003‡	.003‡	.004‡
Male		.038‡	.038‡	.039‡
Northeast resident		−.014	−.012	−.023
Midwest resident		−.009	−.008	−.018
Southern resident		−.010	−.008	−.009
Suburban residence		−.001	−.002	−.002
Rural residence		−.005	−.002	−.002
Income (in thousands)			.000	−.001†
Maternal education (y)			.010‡	.009‡
Has usual source				.094‡
Insured				.043‡
N	14 370	14 370	14 370	14 370
F	49‡	15‡	16‡	20‡
R^2	.007	.010	.012	.018

* Dependent variable is coded as 1 if the child has a chronic condition, and 0 if not. Reference category for black and Hispanic is white non-Hispanic; reference category for Northeast, Midwest, and South is West; reference category for suburban and rural is urban. Reference category for male is female. Reference category for usual source is no usual source. Reference category for insured is uninsured.
† Significant at .05 level.
‡ Significant at .01 level.

TABLE 4. Prevalence of Specified Chronic Conditions Among Children Younger Than 18 Years: United States, 1988*

Condition	Cases/1000			
	All†	White	Black	Hispanic
Musculoskeletal impairments	15.2	15.8	10.6	15.2
Deafness and hearing loss	15.3	18.0	6.0‡	15.2
Blindness and vision impairment	12.7	13.8	8.7‡	13.3‡
Speech defects	26.2	24.0	34.5	35.4
Cerebral palsy	1.8	1.7	0.4‡	3.2‡
Diabetes	1.0‡	1.3‡	<0.1‡	0.3‡
Sickle cell disease	1.2‡	<0.1‡	7.1‡	0.3‡
Anemia	8.8	8.9	9.2‡	7.5‡
Asthma	42.5	42.0	51.3	35.1
Respiratory allergies	96.8	114.7	53.6	47.4
Eczema and skin allergies	32.9	36.7	21.7	19.2
Epilepsy and seizures	2.4	1.9	2.4‡	6.2‡
Arthritis	4.6	4.8	5.4‡	2.0‡
Heart disease	15.2	18.3	7.7‡	10.0
Frequent or repeated ear infections	83.4	94.2	53.8	69.7
Frequent diarrhea/bowel trouble	17.1	17.7	12.9	18.5
Digestive allergies	22.3	27.0	9.9	8.4‡
Frequent or severe headaches	25.3	28.4	21.1	14.7
Other	19.8	23.6	10.2	9.2‡

* Source: original tabulations of the 1988 National Health Interview Survey.
† Includes white, black, Hispanic, and other races.
‡ Indicates prevalence estimate has a relative standard error in excess of 30%.

The results, illustrated by race and ethnicity in Figure 1, confirm our suspicions from the condition-specific analysis: whites were far more likely to report mild conditions than black or Hispanic children ($P < .01$); somewhat more likely to report conditions of moderate severity ($P < .05$); but no more likely to report severe conditions. Hence, although mild conditions are more commonly reported for white children than minorities, there appears to be little in the way of racial or ethnic differences in reporting of conditions with significant adverse impacts on children's daily lives.

Impact of Childhood Chronic Conditions on Use of Medical Services

We assessed use of ambulatory physician services, physician-recommended medications, and inpatient hospital care for children with chronic conditions. In 1988, chronically ill children of all races and ethnicities combined averaged slightly less than 5 ambulatory physician contacts annually for the treatment of their chronic conditions. In addition, 4% of chronically ill children were hospitalized for treatment of chronic conditions during the year before the inter-

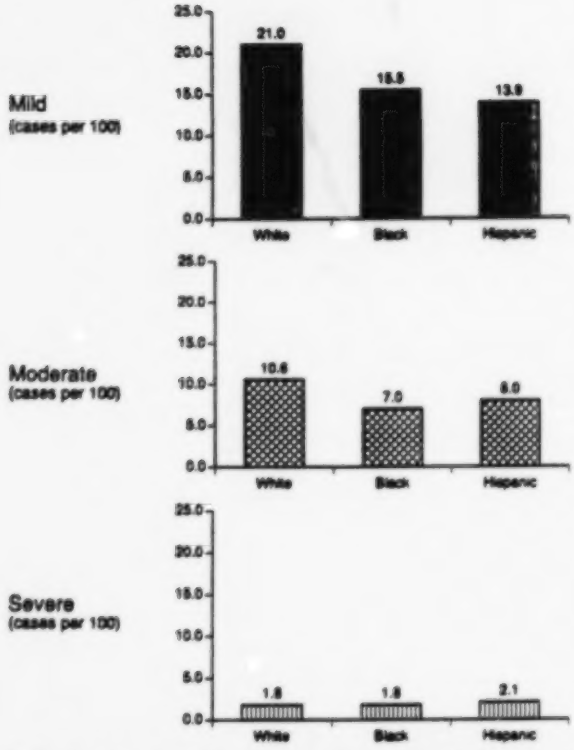

Fig 1. Prevalence of childhood chronic conditions. Mild, children with conditions associated with only occasional bother or no bother and no limitation of activity; Moderate, children with conditions associated with more than occasional bother *or* limitation of activity; Severe, children with conditions associated with more than occasional bother *and* limitation of activity. Source: 1988 National Health Interview Survey on Child Health.

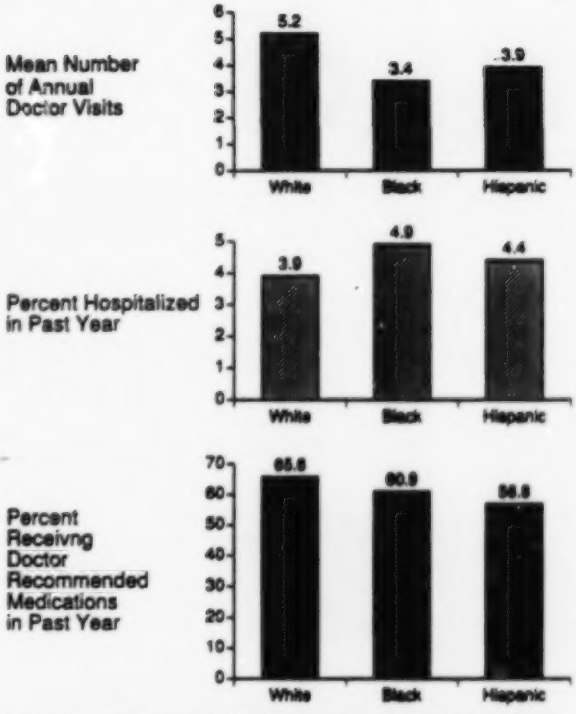

Fig 2. Adjusted mean utilization rates for children with chronic conditions. Mean use calculated by regression analysis. Source: 1988 National Health Interview Survey on Child Health.

view. Finally, 63% of all children with chronic conditions were reported by their parents to have used medications prescribed or recommended by a doctor (excluding vitamins). Routine preventive care and services obtained in treating acute conditions are excluded from these figures. Hence, these results illustrate the added health care burden of childhood chronic illness.

Because severity levels varied by race and ethnicity, use of medical services among white, black, and Hispanic children was not compared directly. Rather, adjusted mean utilization levels were computed via a regression model that accounted for the child's age, gender, race and ethnicity, and severity of illness as measured by frequency of bother and limitation of activity. Adjusted mean utilization rates are presented in Fig 2 for white, black, and Hispanic children with chronic conditions.

Minority children used significantly fewer ambulatory physician services on average than white children. Specifically, blacks had only 65% as many physician contacts as whites ($P < .01$). Hispanic children with chronic conditions were reported to have only 75% as many visits as whites, but this difference was not statistically significant ($P = .09$). Although there were no significant differences in hospitalization rates, both minority groups were significantly less likely than whites to receive medications for their chronic conditions ($P < .05$).

Another dimension of access to health care is examined in Table 5. This table illustrates differences in presence and location of usual sources of routine and sick care for chronically ill children. The vast majority of chronically ill children had a usual source for routine care in 1988, and only minor differences are apparent across racial and ethnic groups. A different pattern emerges for usual source of care for illness. Although almost all children with chronic conditions had a usual source for sick care, the locations at which chronically ill children receive their care when sick varied by race and ethnicity. Hispanic children were more than twice as likely as white children to receive care when sick in a hospital emergency department ($P < .05$). Black children were more than three times as likely as white youth to receive their care in emergency departments ($P < .01$). Taken together, these findings on utilization of health services and usual sources of care suggest that access to health care, especially ambulatory care, varies by race and ethnicity.

DISCUSSION

Findings Regarding Differences in the Prevalence of Chronic Conditions

Results from this investigation suggest that childhood chronic conditions are quite common in the United States. Using a broad definition of chronic illness, approximately 31% of all children younger than 18 years of age were classified as having chronic

TABLE 5. Access to Health Care for Children with Chronic Conditions Younger than 18 Years: United States, 1988*

Access Measure	All†	White	Black	Hispanic
Usual source of routine care				
Percent with a usual source of routine care	92.6	92.7	94.2	90.2
Usual source of sick care				
Percent with a usual source of sick care	95.6	95.9	95.4	93.4
Percent with hospital emergency department	3.5	2.4	9.0	6.1

* Source: original tabulations of the 1988 National Health Interview Survey.
† Includes white, black, Hispanic, and other races.

conditions in 1988. We found large differences in prevalence among the three racial ethnic groups. White children were 37% more likely than black and 39% more likely than Hispanic children to be reported to have one or more chronic conditions. However, most of this difference seems to be attributable to greater reporting of mild chronic conditions—conditions that result in little bother or activity limitation—on the part of white families. We found no significant differences in the prevalence of severe conditions among the racial and ethnic groups studied.

Our condition-specific prevalence findings support this conclusion. Specifically, much of the aggregate prevalence differential between white and minority children can be attributed to the substantially higher prevalence among white children of several common but generally minor childhood conditions, including respiratory allergies, skin allergies, digestive allergies, and repeated ear infections. Although bothersome, these conditions often resolve over time and typically do not result in long-term disability.

Our findings are consistent with previously reported epidemiologic findings concerning racial differences in the prevalence of respiratory allergies and middle ear infections. A higher prevalence of allergic rhinitis (hay fever) among whites relative to blacks was demonstrated previously using clinical examination data from a nationally representative sample.[19] Similarly, a recent review documented higher prevalence rates of otitis media in white children compared with black children.[20]

In reviewing our prevalence results it is important to remember that these data are based on household interviews, not diagnostic tests or medical examinations. Thus, the NHIS results represent the mother's or other adult's perception of the child's health. Parents may have forgotten information, or may be unwilling to report certain potentially embarrassing or stigmatizing health problems for their children (reporting error). Similarly, parents may not be aware of certain health problems, especially "invisible" or asymptomatic conditions (ascertainment error). This may be the case especially for families with limited access to health care. To the extent that these errors vary by race and ethnicity, our conclusions regarding prevalence differences among racial and ethnic groups may be inaccurate.

Although validation studies have been undertaken by NCHS, none have focused on children. The most recent study of reporting error among adults in the NHIS compared interview findings with medical records for members of maintenance organizations. That review found that up to half of all conditions were underreported when compared to medical records, while between 8% and 12% of conditions were overreported when compared to medical records. Of importance, reporting rates were found to vary only slightly by the demographic and socioeconomic status of the respondent. Black respondents, for example, reported 49% of medically identified conditions, while white respondents reported 55% of the conditions found in medical records. These results suggest that reporting errors vary only minimally by race among those with an established health care provider.[21,22]

Findings Regarding Differences in Use and Access to Health Care

We found considerable variation in health care utilization patterns for white, black, and Hispanic children. Our results indicate that white children with chronic conditions used ambulatory care services at much higher rates than black or Hispanic children, even though minority children appear to experience more severe conditions. Indeed, after adjusting for need, our analysis revealed that among chronically ill children, whites used 53% more ambulatory physician services than blacks and 33% more than Hispanics.

The lower utilization rates for physician services on the part of minority children may be the result of economic barriers, such as inadequate income or lack of health insurance coverage. Nonfinancial barriers related to physician supply (especially availability of culturally competent providers), transportation difficulties, child care needs, and other factors may also play a role in limiting access to physician services.

On a more positive note, black and Hispanic youth with chronic conditions were as likely as whites to have usual sources for routine and sick care. However, the locations where that care was received differed markedly. Minority children with chronic conditions, especially blacks, were far more likely than whites to have a hospital emergency department as their usual source of care when ill. Clearly, this represents an undesirable choice, both from clinical and economic vantage points.

Future Research Directions

Our findings suggest that both prevalence of chronic conditions and access to health services vary for white, black, and Hispanic children. Our analysis was based on data collected from the largest population-based survey of childhood chronic conditions conducted during the last decade. In spite of this, our

ability to assess prevalence differences and access barriers was hampered by insufficient numbers of sample cases for minority children.

To develop timely and effective public policies toward meeting the health needs of minority children with chronic conditions, reliable information is needed on the prevalence and impact of their conditions. This can only be achieved through larger survey samples of minority youth, including blacks, Asians, Native Americans, and Hispanics. One promising avenue is the planned 1994–95 National Health Interview Survey on Disability. This survey will provide prevalence and other information on chronic illness for a sample of more than 60 000 children. With a sample of this size, it should be possible to examine the characteristics of black, Asian, and Hispanic children with chronic conditions in a manner that has not been possible to date.

Finally, there is a clear need to conduct validation studies for children in the future. Existing validation studies have focused exclusively on adults. Relatively little is known about how families of different races and ethnicities conceptualize chronic illness in childhood. Those studies that have been completed in this area suggest that there are substantial cultural differences in the conception of chronic illness.[23]

APPENDIX 1. Conditions Considered Chronic

Condition Category	Checklist Conditions Included
Musculoskeletal impairments	Missing limbs, fingers, or toes*; permanent impairment, stiffness or deformity of back or side, limbs, fingers, or toes*
Deafness and hearing loss	Deafness or trouble hearing in one ears*; deafness or trouble hearing in both ears*
Blindness and vision impairment	Blindness in one eye*; blindness in both eyes*; crossed eyes*; any other trouble seeing*
Speech defects	Stammering or stuttering; any other speech defect
Cerebral palsy	Cerebral palsy*
Diabetes	Diabetes*
Sickle cell disease	Sickle cell anemia*
Anemia	Anemia
Asthma	Asthma*
Eczema and skin allergies	Eczema or any other skin allergy*
Epilepsy and seizures	Epilepsy or convulsions without fever*
Arthritis	Arthritis or other joint problem*
Heart disease	Congenital heart disease*; any other heart disease or condition*
Frequent ear infections	Frequent or repeated ear infections
Frequent diarrhea/bowel trouble	Frequent or repeated diarrhea or colitis; any other persistent bowel trouble
Digestive allergies	Any food or digestive allergy
Frequent or severe headaches	Frequent or severe headaches, including migraines
Other	Mononucleosis; hepatitis; meningitis; rheumatic fever*; seizures associated with fever; other bone, cartilage, muscle, or tendon problem; conditions requiring surgery; conditions lasting more than 3 mo

* Denotes conditions deemed chronic regardless of date of onset; other conditions deemed chronic if present more than 3 months.

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APPENDIX 2:

Questions Used to Determine Impact of Childhood Conditions

1. During the past 12 months, about how many nights did ____ spend in the hospital because of (*condition/AIP*)?
2. During the past 12 months, about how many times did [____/anyone] see or talk to a medical doctor or assistant about this (*condition/AIP*)? (Do not count doctors seen while an overnight patient in a hospital.)
3. During the past 12 months, did this (*condition/AIP*) make it necessary for ____ to use any medicine, other than vitamins, that a doctor prescribed OR told ____ to take?
4. In the last 12 months, how often did [this condition/the conditions resulting from the (*AIP*)] cause ____ pain or discomfort or upset — all of the time, often, once in a while, or never?
5. When this condition did bother ____, was ____ bothered a great deal, some, or very little?

Note: *AIP* refers to accidents, injuries, or poisonings.

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Health Insurance Differentials Among Minority Children With Chronic Conditions and the Role of Federal Agencies and Private Foundations in Improving Financial Access

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ABBREVIATIONS. NHIS, National Health Interview Survey; NHIS-CH, NHIS on Child Health; DHHS, Department of Health and Human Services; HCFA, Health Care Financing Administration; MCH, Maternal and Child Health; MCHB, Maternal and Child Health Bureau; SPRANS, Special Projects of Regional and National Significance; SSI, Supplemental Security Income; EPSDT, Early and Periodic Screening, Diagnosis, and Treatment; ORD, Office of Research and Development; SSA, Social Security Administration; NIDRR, National Institute of Disability and Rehabilitative Research.

Minorities experience a disproportionate share of the financial barriers resulting from higher rates of uninsuredness and a greater reliance on Medicaid vs private insurance. As a result, health services use and patterns of expenditures vary markedly by race and ethnicity.[1,2]

National survey data reveal a rapid increase in the number of uninsured black and Hispanic persons between 1977 and 1987.[3] The major factors contributing to this increase are (1) overall growth in the size of the minority population, especially Hispanics; (2) reductions in private insurance coverage; and (3) the lack of significant expansions in public programs, largely Medicaid (note: several Medicaid eligibility expansions affecting poor children occurred during and after 1987).

In 1987, 14% of white children younger than age 18 were uninsured compared to 22% of black children and 33% of Hispanic children (Cornelius LJ. Unpublished data). Black and Hispanic persons were more likely to rely on Medicaid as their primary financing source than were white persons.[3] In 1987, 8% of white children were covered by Medicaid vs 38% of black and 28% of Hispanic children (Cornelius LJ. Unpublished data from the Agency for Health Care Policy and Research, 1992.). Despite Medicaid's importance as a financing source, low reimbursement rates have resulted in inadequate provider participation and corresponding access barriers.[4,5]

In comparison with white persons, minorities have less access to employer-based insurance benefits. Part of the reason lies in the types of jobs that are disproportionately held by minorities. Personal service and agricultural employers typically do not offer health insurance to their employees. Thus, many poor and near-poor minority families are caught either because they are ineligible for Medicaid due to their employment and/or income status or because their employers seldom offer health insurance.

Another factor affecting Hispanics particularly is that many reside in Southern states like Texas, with very stringent Medicaid eligibility criteria, restricting coverage to the very poor.[6] Moreover, many Hispanics and other minorities are ineligible for Medicaid because of their citizenship status.

Little has been written about financial access differentials affecting minority youth with chronic illness. The literature instead addresses financing of care for disabled children as a group[7] or for certain population subgroups, such as adolescents[8] or poor youth.[8,9] A body of literature also exists on minority health status, but few references are available on the health insurance status of minorities. What has been published generally describes coverage of persons younger than age 65, with no detailed information on children.[3,6,10]

The purpose of this article, therefore, is to present new information on health insurance differentials among white, black, and Hispanic youth with chronic illness. Using nationally representative household survey data (the 1988 National Health Interview Survey on Child Health), we examine differences in health insurance status among chronically ill children by race and ethnicity. We describe how insurance status varies by several sociodemographic measures, including poverty and region.

National health insurance estimates of chronically ill children are supplemented by a review of the priorities and grant programs of federal agencies and private foundations which are aimed at reducing financial access barriers. We conclude with policy recommendations for improving health insurance coverage for children with special needs who are from culturally diverse backgrounds.

METHODS

This article is divided into two sections: (1) a review of national data on health insurance, and (2) a summary of the role of several federal agencies and private foundations in reducing financial access barriers.

The first section, describing the health insurance status of white, black, and Hispanic children, is based on data from the 1988 National Health Interview Survey on Child Health (NHIS-CH), a special supplemental questionnaire to the National Health Interview Survey (NHIS). The NHIS is a continuing nationwide household survey conducted by the US Bureau of the Census for the National Center for Health Statistics. Interviews of the parents of 17 110 randomly selected children, ranging in age from newborn to 17 years, were conducted for the child health supplement. The sample of children is representative of the US civilian noninstitu-

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tionalized population. Black families were oversampled to ensure more precise estimates. Interview respondents were primarily mothers of the sample children. A detailed description of this survey can be found in a companion paper, in this issue.[11] Both articles use the same sample and sociodemographic terms to describe the chronically ill child population.

The NHIS-CH provides an estimate of the health insurance status of children. At the time of the interview, respondents were asked about their coverage and were classified accordingly despite changes in coverage that may have occurred earlier in the year. Such average point prevalence estimates generally result in lower estimates of the population with coverage compared to other estimation techniques that incorporate a longer reference period, such as coverage anytime during the past year.

Respondents were asked the following health insurance questions:

1. Did ____ receive any health care which has been or will be paid for by Medicaid?
2. Was ____ covered at any time by Medicaid?
3. Is ____ now covered by a health insurance plan which pays any part of a hospital, doctor's, or surgeon's bill?

From these questions it is possible to produce reasonable estimates of the insured and uninsured child populations. We classified children as insured if a positive response occurred for any of the three questions above. We classified children as having Medicaid coverage if a positive response to either question 1 or 2 was obtained. However, the last coverage question (No. 3 above) does not distinguish whether the respondent's health insurance plan was private or public. As a result, it is impossible to determine accurately how many youth were privately insured in 1988. Hence, we do not present separate estimates of the privately insured population.

The second section, describing the role of federal agencies and private foundations, is based on a telephone interview survey of key agency staff and reviews of grant abstracts and other program materials. We limited this investigation to financing issues. As a result, many public and private efforts dealing with systems development and service delivery related to culturally diverse populations are excluded from this paper.

RESULTS

Health Insurance Differentials: National Data Analysis

Overall Health Insurance Differentials

In 1988, 88% of children younger than 18 years of age with one or more chronic conditions had some form of health insurance protection (Table 1, Figure). Most children were covered by private insurance, and approximately 14% of youth were enrolled in Medicaid. This latter group of publicly insured children may or may not have been privately insured as well. Still, 12% or 2.3 million chronically ill children were uninsured in 1988.

TABLE 1. Health Insurance Status of Chronically Ill Children: United States, 1988

Insurance Status	Percent Distributions			
	All Children	White	Black	Hispanic
Insured	88.2	89.7	86.8	79.9
Medicaid	14.0	8.4	40.1	25.0
Uninsured	11.8	10.4	13.2	20.2

TABLE 2. Sociodemographic Characteristics of Uninsured Chronically Ill Children: United States, 1988

Sociodemographic Characteristics	Percent Uninsured		
	White	Black	Hispanic
Age			
<10 y	11.1	11.9	22.2
10–18 y	9.5	15.0	17.3
Gender			
Male	10.9	12.2	23.9
Female	9.7	14.4	15.4
Region			
Northeast	6.0	9.1	6.2
Midwest	8.0	8.9	2.7
South	14.5	17.3	32.2
West	11.5	5.8	20.3
Residence			
Central city	11.8	12.5	18.5
Suburbs	8.5	14.2	22.6
Non-MSA*	12.7	13.8	19.3
Income			
At or above poverty level	8.4	11.6	18.7
Below poverty level	22.6	14.8	25.4
Maternal education			
<12 y	19.7	16.8	30.9
12 y	10.3	13.4	13.7
>13 y	7.1	10.3	12.4
Parents in household			
One or none	13.8	13.3	17.9
Two	9.4	13.0	21.3
Perceived health status			
Excellent or very good	9.4	11.8	17.4
Good, fair, or poor	12.9	14.4	26.0

* Non-Metropolitan Statistical Area.

Differences in insurance status were revealed among the three racial and ethnic groups studied. Although white and black children were equally likely to have some form of insurance coverage (approximately 9 out of 10 had some form of insurance

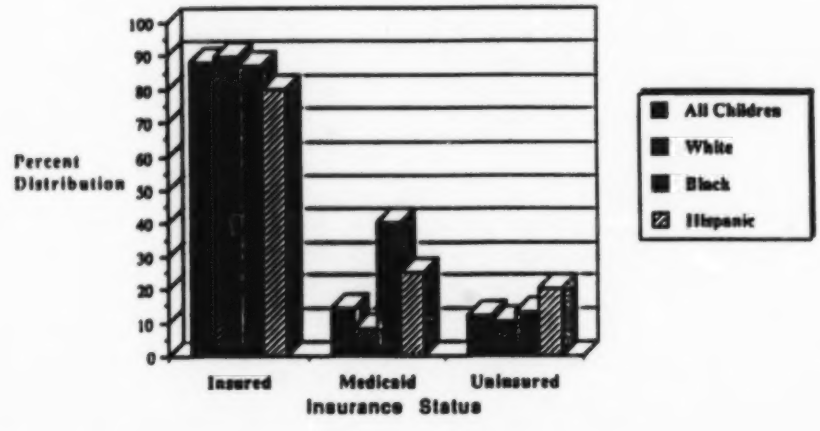

Figure. Health insurance status of chronically ill children: United States, 1988.

TABLE 3. Sociodemographic Characteristics of Medicaid-Insured Chronically Ill Children: United States, 1988

Sociodemographic Characteristics	Percent Medicaid-Insured		
	White	Black	Hispanic
Age			
<10 y	9.4	45.2	26.5
10–18 y	7.1	33.1	22.9
Gender			
Male	7.9	40.5	21.1
Female	8.9	39.7	30.0
Region			
Northeast	6.9	45.0	47.6
Midwest	10.4	52.2	31.0
South	7.0	34.1	13.4
West	9.0	35.3	22.9
Residence			
Central city	11.3	47.3	27.5
Suburbs	5.3	27.5	18.9
Non-MSA*	11.9	36.2	33.6
Income			
At or above poverty level	3.1	14.5	6.6
Below poverty level	50.4	73.6	67.6
Maternal education			
<12 y	30.4	66.2	38.9
12 y	7.4	37.0	23.0
>13 y	3.2	19.2	8.7
Parents in household			
One or none	23.8	54.4	45.7
Two	4.1	16.3	14.5
Perceived health status			
Excellent or very good	6.2	34.1	21.3
Good, fair, or poor	15.2	46.9	32.9

* Non-Metropolitan Statistical Area.

protection), large differences were found in the type of insurance used by these children. An insured black child with chronic conditions was five times more likely than his or her white peers to be covered, at least in part, by Medicaid.

One of five Hispanic children with chronic illness was uninsured in 1988—twice the rate of white youth. Moreover, an insured Hispanic child was three times more likely to be covered by Medicaid than his insured white peer.

Variation by Sociodemographic Characteristics

To further assess racial and ethnic differences among uninsured and Medicaid-insured children, we examined several sociodemographic characteristics, as shown in Tables 2 and 3. Readers should keep in mind that a limited number of sample observations was available for the analysis, resulting in relatively large standard errors. Hence, some of the variability found among the racial and ethnic groups is likely to be attributable to sampling variability.

Uninsured Children. No substantial age or gender differences were discovered among white and black uninsured youth with chronic conditions (Table 2). Both age and gender differences, however, were found among Hispanic youth. Hispanic males and younger children (younger than 10) were more likely to be uninsured.

Chronically ill children residing in the South were most likely to be uninsured. White and black Southern youth were twice as likely to be uninsured as those living in the Northeast or Midwest. Hispanic youth from the South were more than five times as apt to be uninsured as those from the Northeast or Midwest.

Residence is also a factor affecting the size of the uninsured white and Hispanic populations, though in opposite directions. Urban and rural white youth were at greater risk of being uninsured than were their suburban peers. In contrast, Hispanic suburban youth were more apt to be uninsured than either urban or rural youth.

Income had its most pronounced effect on the insurance status of white youth with chronic conditions. A white child whose family's income was below the poverty level ($11 611 for a family of 4 in 1988) was almost three times as likely to be uninsured as one whose family's income was above the poverty level (22.6% vs 8.4%). Poor Hispanic youth were also at greater risk for being uninsured than were their nonpoor peers, though the difference was not as great as among white youth (25.4% vs 18.7%). Surprisingly little difference was discovered among black youth by family income status (14.8% vs 11.6%). Again, however, these differences are based on small sample numbers.

Maternal education had a marked effect on the insurance status of all chronically ill children, with the greatest margin of difference found among white and Hispanic children. Specifically, mothers with fewer than 12 years of education were at much greater risk of being uninsured than mothers with more than a high school education.

The number of parents in the households surveyed affected both white and Hispanic children, though conversely. White children with one or no parents were more apt to be uninsured than white children from two-parent households (13.8% vs 9.4%). This is in contrast to Hispanic children with two parents, who were at greater risk of being uninsured than their peers with one or no parents (21.3% vs 17.9%).

A consistent pattern in perceived health status was found among all chronically ill children. Those children reported to be in only good, fair, or poor health were more likely to be uninsured than those in excellent or very good health. Specifically, an estimated 1 million white youth, 546 000 black youth, and 559 000 Hispanic youth in good, fair, or poor health were without any health insurance protection in 1988.

Medicaid-Insured Children. Medicaid coverage by race and ethnicity also varied significantly according to several sociodemographic factors, as shown in Table 3. Younger chronically ill youth of all races and ethnicities were more apt than their adolescent peers to be covered, at least in part, by Medicaid, which is not surprising in light of the federal mandates to immediately cover younger children and to gradually phase-in coverage of older children. The greatest age difference was found among black youth (45.2% of 10- to 18-year-olds were Medicaid-insured vs 33.1% of those younger than 10). Only among Hispanics was a gender difference found in Medicaid coverage. Thirty percent of Hispanic females were Medicaid-insured compared with only 21% of Hispanic males.

White and black chronically ill children from the Midwest were more apt to be insured by Medicaid than children from any other region of the country. Hispanic children from the Northeast were more likely to be covered by Medicaid.

Medicaid coverage varied by residence among all groups studied, with suburban youth being the least likely to be enrolled in Medicaid. White youth from urban or rural areas were twice as apt to be Medicaid-insured as those residing in the suburbs. Urban and rural black youth were 72% and 32% more likely to be covered by Medicaid than suburban black youth. In contrast, urban and rural Hispanic youth were 46% and 78% more likely to be covered by Medicaid than suburban Hispanic youth.

As expected, income had a strong effect on Medicaid coverage for chronically ill children of all races. Poor white youth were 16 times more likely to be covered by Medicaid than nonpoor whites. A 10-fold difference in Medicaid coverage was found among poor vs nonpoor Hispanic children in 1988. Among black youth a 5-fold difference was revealed by poverty status.

Similarly, a consistent pattern was uncovered for maternal education characteristics among children of all races. The less education the mother had, the more likely her children were to be insured by Medicaid.

In the past, Medicaid was largely restricted to single-parent households. Not surprisingly, the 1988 NHIS-CH results reveal that children residing in one- or no-parent households were far more likely to be Medicaid-insured than those living with two parents.

Finally, chronically ill children of all races and ethnicities reported to be in good, fair, or poor health were more apt to be covered by Medicaid than those in excellent or very good health.

Role of Federal Agencies and Private Foundations in Improving Financial Access

The foregoing review of recent national health insurance data has pointed out significant gaps in insurance coverage for minority children with chronic conditions and, consequently, gaps in their access to care. In what follows we assess the roles of several government programs and private foundations in improving financial access to care. To do this, we interviewed agency staff and reviewed program documents on current financing-related priorities and grants. The reader should keep in mind that our focus was limited to financial access, not to systems development and service delivery related to culturally diverse populations. If these latter topics had been included, a far different agency picture would have emerged.

DHHS Secretarial Initiatives

The Department of Health and Human Services (DHHS) has developed a series of national goals and objectives on disease prevention and health promotion for the year 2000. Only two objectives directly address the financing of services related to children:

1. Immunization and infectious diseases: "Improve the financing and delivery of immunizations for children and adults so that virtually no American has a financial barrier to receiving recommended immunizations."
2. Clinical preventive services: "Improve financing and delivery of clinical preventive services so that virtually no American has a financial barrier to receiving, at a minimum, the screening, counseling, and immunization services recommended by the US Preventive Services Task Force."

Despite the fact that DHHS has developed national goals addressing financial access for preventive care, no specific national objectives relate to financial access for the diagnosis and treatment of health problems affecting children (or any age group).

Dr Louis Sullivan, the former secretary of DHHS, has also issued a separate, but related series of recommendations or priorities related to minority health. The purpose of this secretarial initiative is to reduce gaps in health care services and health status. Of greatest relevance to financial access is Program Direction 9: "Improve the health status of minority and low-income persons, and reduce disparities in the incidence of premature death, chronic diseases, and injuries." A two-part strategy has been developed to implement this priority. The first part is directed at improving access to services for minority and low-income populations, especially pregnant women and infants.

The Office of Minority Health (described below), along with other agencies of the Public Health Service, the Health Care Financing Administration (HCFA), the Administration on Children and Families, and the Office of Civil Rights, is assuming a leadership role in coordinating the DHHS plan to improve access. The specific objectives and actions related to financing are listed below:

- Increase the enrollment of eligible pregnant women and infants in Medicaid.
- Enhance eligibility determination and service provision by encouraging "one-stop shopping" sites.
- Encourage enrollment of pregnant women into coordinated care systems to provide access to providers and appropriate level of care.

These federal directives have focused on Medicaid and pregnant women and infants. While these directives may reduce the prevalence of congenital chronic conditions, no specific priorities have been set for improving Medicaid coverage of children and adolescents with special health care needs. Moreover, no action steps have been developed to increase private health insurance coverage of minority children.

Office of Minority Health

The Office of Minority Health was established in 1985 to reduce health status disparities between minorities and nonminorities. Particular attention has been focused on closing the gaps among seven major causes of death, four of which relate to children: infant mortality; chemical dependency; homicide, suicide, and unintentional injuries; and human immunodeficiency virus infection and acquired immunodeficiency syndrome.

No Office of Minority Health grants have been directed at improving the health insurance coverage of minorities. Much of their attention has instead focused on coordinating efforts within the federal government to promote minority health and establishing the infrastructure of community-based, minority organizations to assume a greater role in disease prevention and health promotion.

Maternal and Child Health Bureau

Originating in 1912, the federal Maternal and Child Health (MCH) program has historically focused on serving medically underserved women and children and children and youth with special health care needs. The purpose of Title V was amended in 1989 with the passage of the Omnibus Budget Reconciliation Act (PL 101-239) to (1) link Title V program goals with the health objectives for the nation related to *all* mothers, infants, children, and adolescents; and (2) strengthen each state's MCH Program and Program for Children With Special Health Care Needs to ensure a health care service system that is family-centered, community-based, culturally sensitive, and coordinated.

As part of the block grant application plan, each state Title V program must conduct a needs assessments every 5 years along with developing plans for meeting its identified needs. Congress specifically requested that state plans include information on the health insurance status of individuals served by block grant programs and the number of children with chronic illness and the type of illness.

The Maternal and Child Health Bureau (MCHB) administers a grant program for Special Projects of Regional and National Significance (SPRANS) supported by 15% of its block grant funds. The four major categories of SPRANS grants funded are: research; training; genetic disease screening, testing, counseling, referral, and information dissemination; and MCH improvement projects.

There are no MCH improvement projects grants directed solely at financing issues affecting minority youth and their families. Most of MCHB's focus on children from culturally diverse populations has instead targeted systems development.[12,13] A few of the more than 200 SPRANS grants dealing with minorities address financing issues as part of a larger program initiative. For example, a Montana case management project develops community-based teams to empower families to better meet their financial needs. This is part of a larger program to enhance the case management skills of public health nurses.

MCHB also funds several financing projects, but the major focus is directed at Medicaid, the Supplemental Security Income (SSI) Program, and private health insurance as it affects all children with special needs or subgroups, such as infants or adolescents. For example, the Maternal and Child Health Policy Research Center (operated by Newacheck, McManus, and Fox) conducts ongoing policy analyses of the health insurance status of all special-needs youth and of trends in Medicaid and private health insurance benefits. Another MCHB resource center, the National Center for Policy Coordination in Maternal and Child Health (operated by Freedman, Reiss, and Siderits), has assumed a leadership role in guiding state Title V Programs for Children With Special Needs in implementing the recent SSI policy changes affecting children. They have also pioneered with developing school-based health insurance programs for uninsured children.

MCHB has cooperative agreements with several national organizations dealing with many issues. Some of them address financing topics, primarily Medicaid (eg, one-stop shopping models, out stationing eligibility workers, obtaining full cost reimbursement). These agreements are with the Association of Maternal and Child Health Programs, the National Governors' Association, the National Conference of State Legislatures, CityMatch, the US Conference of Mayors, the US Conference of Local Health Officers, the National Association of County Health Officers, the Healthy Mothers/Health Babies Coalition, and the Washington Business Group on Health (related to the private purchasing community).

Other Federal Agencies

Several other federal agencies have responsibilities for financing issues related to minority children with special health care needs. These agencies are briefly described below.

The Health Care Financing Administration (HCFA), which administers Medicaid and Medicare, has several relevant activities under way within their Offices of Medicaid Policy and Research and Development. None of the efforts described below, however, are directed specifically at minority children with chronic conditions. HCFA, as part of the Secretary's Program Direction No. 9, is supporting five small Medicaid projects to develop model outreach programs for minority populations. They are also working with other Public Health Service agencies to improve the infrastructure of federal and state public health and Medicaid agencies in the areas of provider recruitment, outreach, and improved use of the Early and Periodic Screening, Diagnosis, and Treatment (EPSDT) Program in selected areas with low immunization rates and high infant mortality rates.

HCFA has an MCH priority area within the grant program operated by the Office of Research and Development (ORD). Most recently, ORD released a request for proposal to compare the use of EPSDT and other preventive and curative health care services by children enrolled in Medicaid. No specific minority analyses were requested as part of this request for proposal. ORD also awarded three grants (in Florida, Maine, and Michigan) to experiment with alternative approaches for extending Medicaid eligibility to cover pregnant women and children younger than 20 with incomes below 185% of the federal poverty level. None of these projects were designed specifically for minority children with chronic illness.

The Social Security Administration (SSA) administers the SSI Program, which is a cash assistance program for low-income blind, disabled, and elderly individuals. Automatic Medicaid eligibility is granted to those who qualify for SSI in all states but New Hampshire. In 1990, SSI was expanded for children

(as a result of the Zebley decision) to allow for more expansive functional assessments of children and to cover more illnesses and abnormalities.

Beginning in 1990, SSA began the Supplemental Security Income Outreach Demonstration Program to develop and test new approaches for reaching and maintaining contact with those who are potentially eligible for SSI. Of the original 33 cooperative agreements awarded, 19 were aimed at specific minority groups but only one was directed at minority children. SSA is planning to award new grants under this program in June of 1992. Since one of their special priority areas is children, SSA expects the number of child-specific projects to increase. They also anticipate awarding several grants to organizations serving minorities, including Hispanics and Native Americans. Finally, SSA is conducting an evaluation of their outreach projects to identify effective and replicable mechanisms and administrative process changes that would improve the use of SSI among underserved populations.

The Department of Education's Office of Special Education and Rehabilitative Services operates the National Institute of Disability and Rehabilitation Research (NIDRR) and the Office of Special Education Programs. The only NIDRR-funded grant that addresses financing issues affecting minority youth is to the University of Minnesota's Center for Children With Chronic Illness and Disability, for whom this paper is being prepared. No other NIDRR financing projects related to minority children are under way.

The Office of Special Education Programs supports a National Early Childhood Technical Assistance System (NEC*TAS), which contracts with Georgetown University's Child Development Center, to offer financial consultation to state lead agencies who are implementing Parts B and H of PL 101-476 (the Individuals with Disabilities Education Act). Georgetown's efforts aim to maximize the use of Medicaid and private health insurance coverage for early intervention and pre-school special education services. To date, their technical assistance financing efforts have not been directed primarily at culturally diverse populations.

Several additional DHHS agencies not included in this summary may also be conducting relevant program activities. These include the Centers for Disease Control, the National Institute of Mental Health's Child and Adolescent Service Systems Program, the Bureau of Health Care Delivery and Assistance of the Health Resources Administration, the Indian Health Service, and the Agency for Health Care Policy and Research.

Private Foundations

More than 300 private foundations support health programs for children in this country. Their grants cover a wide range of services, from adolescent pregnancy prevention to drug abuse treatment programs. The Foundation Center prepares grant guides which provide a general overview of foundation support on given subject areas.

Grants for Health Programs for Children and Youth describes grants for children funded in 1989 and 1990. Of the 360 foundations described in the grant guide, none had funded projects directed specifically at improving financial access among minority children with chronic conditions. Only 14 foundation-funded projects were related to minority children with chronic illness. The Packard Foundation and the San Francisco Foundation were the only two that addressed financing issues primarily affecting poor children. The Packard Foundation funded the Youth Law Center in San Francisco to research public and private insurance barriers experienced by medically vulnerable children and their families. The San Francisco Foundation supported the Children's Research Institute to monitor the implementation of Medicaid's preventive care program for poor children in five Bay Area counties.

Three other foundations supported the greatest number of projects related to minority children, though none dealt with financing per se—the W.K. Kellogg Foundation of Michigan, the Robert Wood Johnson Foundation of New Jersey, and the William T. Grant Foundation of New York. Since the bulk of our foundation information is 2 years old, readers should be advised to keep in mind that foundations' priorities change and new grants are distributed regularly, some of which may directly or indirectly relate to financing issues for culturally diverse children with special health care needs.

DISCUSSION AND RECOMMENDATIONS

Health Insurance Differentials

Marked racial and ethnic differences can be seen in the health insurance status of chronically ill children. Hispanic children with chronic illness are at greatest risk for being uninsured. Efforts to reduce the high rates of uninsuredness among Hispanic youth (20%) should focus particular attention on children residing in the South and West, whose family incomes are below the poverty level, whose mothers have less than 12 years of education, and whose health is good, fair, or poor.

Among the 13% of black chronically ill children who are uninsured, special efforts should be targeted to children residing in the South, who have family incomes below poverty, whose mothers have not graduated from high school, and who are in good, fair, or poor health.

Among the 10% of uninsured white chronically ill children, initiatives to extend coverage should focus on the South and West, urban and rural areas, on poor families, on single-parent families, and on children whose health status is good, fair, or poor.

Tremendous racial and ethnic disparities can be seen in chronically ill children's source of payment, with black and Hispanic children far more likely to be covered by Medicaid than white youth. Employer-sponsored health insurance is apparently unavailable to large proportions of black and Hispanic families with chronically ill children. To what extent this disproportionate reliance on Medicaid among black and Hispanic chronically ill children can be ex-

plained by their employment and poverty status is unclear. Moreover, Hispanic youth were far less likely than black youth with chronic conditions to have Medicaid coverage. Thus, if poverty rates among black and Hispanic youth are similar, other barriers are restricting access to Medicaid among Hispanics.

State and federal health insurance proposals must create incentives and mandates to require all types of employers, including those in service and agricultural industries, to offer health insurance. Much of the current public policy discussion has been limited to employer incentives to enable small businesses to offer affordable health insurance. Mandates must be given greater consideration, not only for small businesses but also for service and agricultural employers, if minority populations are to gain universal coverage. In addition, use of means-tested premiums, deductibles, and other cost-sharing requirements needs to be promoted within existing insurance mechanisms and in new reform proposals.

Role of Federal Agencies and Private Foundations in Improving Financial Access

In recognition of the serious financial barriers experienced by uninsured chronically ill children, particularly Hispanic youth, and the marked differences in type of insurance coverage among black and Hispanic youth vs white youth, we explored what activities and grants federal agencies and private foundations are supporting to address these problems.

No federal agency or private foundation has supported any major initiative aimed directly at reducing financial access problems of minority children with chronic illness. A comprehensive agenda has not been developed for setting program priorities and agency responsibilities to ensure that all chronically ill children from culturally diverse populations have access to either private health insurance or public coverage.

Federal agencies and private foundations have already made substantial contributions in related issues, such as financial access, enhancement of services for culturally diverse populations, and improving systems of care for children with special health care needs. The challenge now will be to effectively build upon the existing priorities and the service networks that are rapidly forming in order to promote improved financial access for minority children with chronic illness. Much of the success of such piggybacking will be based on (1) working within the interagency networks already established by the federal government, state agencies, and community-based organizations; (2) articulating goals and action steps within existing national goals, program directions, policy manuals, state plan requirements, and grant applications; (3) identifying the capacities of existing grantees to further the mission of improved financial access; and (4) developing partnerships with selected foundations and other private and public organizations to ensure a financial infrastructure for all culturally diverse children and families with special health care needs.

The following is a partial list of financing recommendations that might be part of a coordinated and comprehensive agenda.

1. Assess the effects of poverty and employment status on access to private health insurance coverage and Medicaid among chronically ill children from culturally diverse backgrounds.
2. Fund a few demonstration projects in selected communities and states in the South and West with lower than expected rates of coverage among Hispanic youth with chronic illness to test different combinations of approaches to improve their financial access. Replicate in other communities.
3. Assess the unique problems among service and agricultural industries regarding their reasons for not offering health insurance to employees. Explore alternative mechanisms for ensuring better coverage among their employees.
4. Develop more aggressive Medicaid outreach strategies for potentially eligible Hispanics and other minority groups. Work with community-based organizations as alternative application sites. Increase the bilingual caseworker capacity at all Medicaid application sites.
5. Explore greater use of premium subsidy programs to enable culturally diverse families to purchase employer-based private health insurance.
6. Ensure that minority families with chronically ill children who are ineligible for private health insurance coverage or Medicaid can gain access to publicly supported health programs.
7. Promote greater private health insurance and Medicaid coverage of outreach, case management/care coordination, and health education within programs serving culturally diverse populations.
8. Inform provider organizations serving minority children with chronic illness about (a) Medicaid provider requirements and the importance of their organizational and staffing arrangements and linkages with other Medicaid providers, and (b) the potential for obtaining Medicaid coverage for their services, with particular attention to the recent changes in the EPSDT Program.
9. Assess the implications of the growing use of Medicaid managed-care arrangements on public health providers and other community-based organizations serving chronically ill children from culturally diverse populations.
10. Inform minority families, particularly those with limited education, about the importance of health insurance and the range of options available to gain coverage.

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Multiculturalism, Chronic Illness, and Disability

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The past two decades have brought significant improvements to the lives of children and adults with chronic illness and disability. Medical, technological, social, and legal advances have shifted the focus from the hospital and the institution out into the community, where all but a small percentage of Americans with chronic illnesses and disabilities will now spend their lives. Moving the frame of reference into "the community," however, raises another set of issues that have yet to be adequately addressed.

Too often, the "community" under discussion in the literature is an abstraction, with the services and networks which are assumed to exist reflecting stereotypical white, middle-class values and concerns. It is now widely acknowledged that these stereotypes do not hold true even for the family structures, support networks, and community resources found within the white middle-class America of the 1990s. We believe that such assumptions are even less helpful in defining the community-based needs of individuals with chronic illness or disability from ethnic and minority communities found throughout our country.

Many ethnic and minority populations, reflecting their own unique and long-standing cultural beliefs, practices, and support systems, do not define or address disability and chronic illness in the same manner as "mainstream" American culture. Their concerns are not necessarily identical, their solutions are not always the same, and the strengths shown in many ethnic and minority groups may present alternative ways of addressing needs that merit our careful attention.[1,2] We strongly argue that to better service children and adults who have a chronic illness or disability within our multicultural society, it is imperative that we understand the cultural beliefs and attitudes that determine behaviors, guide decisions, and effect interactions with the broader society. This should include the fact that our own traditional "American" way of addressing issues of chronic illness and disability is, in itself, not culture-free, but a unique product of our nation's history, legal system, and social structure.

The concept of cultural sensitivity and compromise is a recent one. Previous waves of immigrants have been called upon to become part of a "melting pot." The popular belief was that whatever beliefs and traditions were brought to the United States by immigrants would quickly disappear, replaced by solidly "all-American" values, attitudes, and behaviors. Social scientists now recognize that each ethnic and minority group that has come or been brought to the United States, from the Pilgrims on, while incorporating much from the broader society, has also tended to retain parts of its traditional beliefs and practices.

The result is that each ethnic and minority group develops a unique mix of cultural roles, expectations, and conceptual frameworks that, in part, determines how its members view its social networks, support systems, and communities. These culturally based belief systems are not simply of scholarly interest, but are real social *facts* which help to shape the decisions made by individuals with a disability or chronic illness and their families.‖

In response to this growing awareness of diversity, health care professionals, educators, employers, and politicians have begun to use the term "multiculturalism" or "cultural diversity" when designing policies, programs, and services intended to meet the needs and expectations of dozens of distinct ethnic and minority groups. However, for a program or a policy to be truly multicultural, there must be a real understanding of the differences within and between cultures.

Too often differing cultural belief systems are approached by the dominant society and by professionals in an oversimplified manner. As members of the dominant American society, they are drawn to what they perceive to be the strange or the exotic way in which people respond to different physical or mental conditions. Understanding differing cultural belief systems can often provide an important conceptual tool when working with children and families in a culturally diverse society.

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‖It is imperative to note that caution must be used in the broad categories currently employed in popular culture (and unfortunately, all too frequently in research as well), when current American ethnic and minority populations are discussed. All but the smallest of cultural groups are themselves further divided into a number of subgroups that are significant in their differences. For example, although African-Americans are often discussed as members of a single group (and all certainly have confronted similar issues of racism), in fact the socioeconomic, educational, and medical needs of the suburban, professional black couple with a disabled child may be significantly different from those of a single, teenage mother and her disabled infant living in an inner-city housing project. "Hispanic" is used both by researchers and in the dominant culture to refer to individuals from any one of over 20 different countries. The social service needs of a disabled child whose parents are college professors from Venezuela may be markedly different from those of Indian parents, speaking a native Indian dialect, here as illegal immigrants from the highlands of Guatemala (parents for whom even Spanish is a second language). "Asian" as it is currently used in the literature too often refers to anyone whose ancestors come from the Orient—a region that includes several dozen major countries and over a third of the world's population. That we can lump together non-European ethnic groups in such a manner speaks to a lack of understanding of these cultures, not to their lack of internal diversity.

THREE KEY ISSUES

An individual's *culture* is not a diagnostic category; no cultural heritage will wholly explain how any given individual will think and act, but it can help health care professionals anticipate and understand how and why families make certain decisions. The understanding and clinical application of cultural difference is a new task for health care professionals. While disability studies is a discipline barely a decade old,[3] our current state of knowledge allows us now to begin to identify key issues concerning the social implications of chronic illness and disability. Among these, the following three issues seem to be almost universal, appearing prominently and consistently in cross-cultural studies:

1. The culturally perceived *cause* of a chronic illness or disability is significant in all cultures studied to date. The reason why an illness or disability is believed to have occurred in a particular individual and/or family will play a significant role in determining family and community attitudes toward the individual.
2. The expectations for survival (usually conceptualized in terms of actual *physical* survival) for the infant or child with a chronic illness or disability will affect both the immediate care the child receives and the amount of effort expended in planning for future care and education.
3. The social role(s) deemed appropriate for disabled or chronically ill children and adults (often based on a consensus about their productive potential and beliefs about how the disability is transmitted) will help determine the amount of resources a family and community *invest* in an individual. This includes issues of education and training, participation in family and community social life, the latitude permitted for individual autonomy, and the long-range planning done by, or undertaken for, the individual over the course of a lifetime.

Culturally Perceived Causes of Disability

The first of these issues, the culturally perceived cause of a chronic illness or disability, is of particular importance because it tends to color all other aspects of the family's and the community's attitudes toward the affected child.

Chronic illness and disability is seen by many cultures as a form of punishment. The individual with a disability, his or her family, or an ancestor, according to the particular belief system, has been either cursed by God or the Gods, sinned, or violated a taboo. Support for the individual or the immediate family in such cases might be half-hearted or lacking. Others may seek to distance themselves from those who have incurred such "evil." This is more than the simple distancing of former friends and relatives frequently reported in the literature by parents of children with disabilities. In some ethnic groups, the child is seen as tangible evidence of divine displeasure, and its arrival is accompanied throughout the community by prolonged public and private discussions about what wrongs the family may have committed.

Nor is divine punishment by any means the only explanation. In a number of African, Caribbean, and Pacific Basin societies, as well as among many Native American tribes, witchcraft is strongly linked to ill health and disability. An individual who has been bewitched is presumed to be a victim, but is not necessarily seen as innocent. The reason for the witch's curse again is subject to public discussion. Close association with such a person, it is believed, may place others at risk for witchcraft. (A version of this is commonly found throughout the Mediterranean basin and Latin America, where a child's serious illness, particularly if it is of rapid onset, is often said to be caused by the "evil eye".)

Inherited disorders and illness are frequently envisioned as being caused by a family curse or as "running in the blood." Within such families, a clinician's desire to determine who is the carrier for a particular gene may be interpreted as an attempt to discover who is at fault, and such an endeavor may be met with great resistance by family members.[4] Bad blood, a widely held European folk belief, was strengthened by the late 19th century eugenics movement, which emphasized the concept of inheritability of tainted and defective genes. Folk ideas mingled with eugenics particularly throughout Western and Southern Europe, giving birth to the widely held belief that many conditions, particularly mental retardation, are the products of intermarriage among close relatives. This traditional belief that a weak or disabled child may be the product of an incestuous relation may further complicate attempts on the part of professionals and advocates to encourage parents and families to come forward for assistance.¶

In societies where belief in reincarnation is strong, such as among Southeast Asian groups or in Indian society, a disability is frequently seen as direct evidence of a transgression in a previous life, either on the part of the parents or the child. Those who are disabled are frequently avoided or discounted because of their past lives, while they are simultaneously urged to lead particularly virtuous lives this time around. Answerable both to the past and the future, too little time and energy are often devoted to improving life in the present.

Not all belief systems emphasize punishment or witchcraft. For example, the belief that chronic illness and disability are caused by an imbalance of elements humors in the body is found in various forms throughout Latin America and Southeast Asia. This belief system places the burden of responsibility for disability with the affected individual. The cause and the potential cure lie within the individual. He or she must try to reestablish his or her own equilibrium,

¶The folk belief in inherited traits also provides an excellent example of how folk medical categories do not always correspond with modern genetic knowledge. A parent discussing his or her family's "bad blood" will not infrequently cite as proof a list of unrelated conditions in an extended family over the course of several generations—a blind great-aunt, a mentally retarded third cousin, and a nephew with cerebral palsy—as evidence of an inherited problem. For believers in the folk concept of bad blood, the specific type of disabling condition is of less importance than the belief in the presence of an underlying and unifying problem.

and by extension good health. An individual with a chronic illness or permanent disability who cannot be fully healed within this conceptual system may be considered to exist in a continually impure or diseased state.

All these perceived causes are linked, for in all of them, the family or the individual who is disabled is held accountable for his or her own problems. As a consequence, the members of a particular community may hesitate to respond to requests to provide assistance or permit social integration. Indeed, in some cultures, it is believed that even mentioning the name of an individual who is ill or disabled puts the discussant at risk for a similar impairment. For example, the widely held European folk belief that a pregnant woman who sees or thinks of an individual with a disability "marks" her baby with the same impairment is still widely found among descendants of English and Irish settlers in the rural South and Yankee New England. In cultures where this belief is particularly strong, even a simple census or community needs assessment survey may miss a significant percentage of those they are trying to reach.

These traditional beliefs do not necessarily disappear simply because a genetics counselor, physician, or special educator explains the way genetic inheritance works or the physiological patterns of progression of a chronic illness. Often, new information is quickly integrated into the traditional system of folk beliefs. An explanation of how a genetic disease spreads through a family may be readily accepted, but does not guarantee that the older belief in a curse, or bad blood, will disappear. For the strong believer, the issue is not only how a disease spreads or a physical or intellectual impairment occurs, but why one particular person out of all those in a family or community is the one affected. Traditional beliefs systems have shown themselves to be particularly adaptable, often successfully integrating the most traditional of beliefs and the most modern of scientific research.

The consequences here are particularly of concern. Where disability is seen either as a divine punishment, an inherited evil, or the result of a personal state of impurity, the very presence of a child or adult with a disability may be something about which the family is deeply ashamed or with which they are unable to cope. Fortunately, even in such societies, abusive behavior toward infants and children, even those with the most severe of disability conditions, is relatively rare.[5] Of greater concern, however, is the issue of neglect—the failure of the parents to nurture and provide adequate ongoing care, education, and emotional support.

Neglect may be reflected in many forms. In some ethnic and minority groups, parents of young children may hesitate to come forward to request aid or advice. Keeping the child at home, unseen even by close family and neighbors, is, by some, considered preferable. This may be done for several reasons. Embarrassment about the child's condition may be only one factor. Equally as common is the practice of keeping a child isolated in an effort by caring parents to protect that child from the jeers and taunts (or feared jeers and taunts) of others.

In many countries, the very notion that a disabled child can be helped by early intervention or stimulation has not become a part of the standard knowledge base, even in the minds of medical and educational professionals. (Indeed, ideas such as early intervention date back only a few decades in our own country, and many parents of significantly impaired teenagers and young adults can still recall being told to "take the child home and love him until he dies.") Unfortunately, particularly in the case of pre-school-age children who may not receive needed interventions and services until they reach mandatory school-age, important developmental years are frequently lost in the process.

In addition to the particular beliefs and understandings of the immediate family, service providers and advocates must be aware that in those ethnic and minority groups where disability is regarded as unacceptable, there is often enormous social pressure placed not only on the disabled child and adult but also on his or her immediate and extended family. Even when families are aware of the need for special services, they may be reluctant to participate in programs, fearing that these will call attention to their members' physical or intellectual limitations. This is of particular concern for pre-school-age children with a chronic illness or disability who are yet to be enrolled in educational programs where their needs will be clearly identified and followed. Often, parents of these children may hesitate or refuse to participate in any programs if their child is not in need of immediate medical care. Where blame is attached to the individual with a disability, families who appear to be uncooperative or unenthusiastic about participating in programs may be basing their actions on a much broader set of social factors than outside program coordinators have considered. For example, when the traditional belief is that a disability runs in a family or is evidence of divine retribution, a family with siblings of marriageable age may be more likely to hide its disabled member away so as not to lessen the changes of finding suitable mates for the other children. In many cases, parents and other family members may fear losing work, social status, or "face" should their child's condition become widely known.

Public disgrace is not the only possible issue involved. Among some immigrant groups, for example, those from parts of Eastern Europe, parents may have real fears that their children will be taken away and institutionalized should they be located by the authorities. This has been standard practice in the countries from which they have recently immigrated, and it represents a real fear on the part of caring parents.

Finally, it must be stressed that some cultural explanations of the cause of chronic disease or disability are quite positive. A recent study of Mexican-American parents of chronically ill children found that the informants believed a certain number of ill and disabled children would always be born in the world.[6] They believed, furthermore, that they had

been singled out by God for the role because of their past kindnesses to a relative or neighbor who was disabled.*

Expectations for Survival

Not only is an understanding of the socially perceived cause of chronic illness and disability important, the accepted body of folk knowledge about the probability for survival by these disabled infants and young adults must also be noted.

An accurate understanding of the traditional expectations about the health and well-being of these children as they grow is imperative. The persistent belief in many societies that more severely disabled children will simply not survive makes the allocation of scare resources such as medical care and parental attention to healthy children seem more reasonable to families. Even today, throughout much of the world, withholding of these necessities turns the cultural expectations into self-fulfilling prophecies. Although sophisticated medical technologies in the United States can now ensure the physical survival of many of these children, the parent's choice either to neglect such children or, conversely, to shower them with love and attention "because they're with us for so short a time" may reflect traditional expectations of survival. Such attitudes, unfortunately, may severely compromise attempts to encourage parents to plan realistically for their child's future. Either neglecting or overprotecting an ill or disabled child can certainly have grave implications for healthy psychological development.

Cultural expectations cannot be divided neatly into groups in which long-term survival is expected vs groups where it is not. How one is believed to be restored to health is also at times an important issue, and it has serious implications for long-term planning. For example, in some African-American households, particularly those that are strongly affiliated with the church, hope for even the most critically ill child is encouraged, with parents hearing from both family and friends that maybe a miracle will occur or that maybe the doctors are wrong. In at least one study this appears to have lead to a far greater acceptance and improved quality-of-life for the child in question.[4] On the other hand, such a belief, while comforting for those who believe, can also complicate long-term planning. Parents planning for a child's surgery, attempting to clarify an educational plan, or arranging for sophisticated adaptive equipment have all reported during interviews that friends and relatives, particularly older relatives, will dismiss long-term concerns by saying: "maybe God will make your baby all better on its own," and "don't worry so, wait for God's word, and all will be made whole."

Expectations of Social Participation

Problems do not end when an individual who may be chronically ill or disabled survives childhood. Where society dictates limited occupational roles and few social roles for individuals with a chronic illness or disability, the time, energy, and expense invested in educating a child with a disability may be regarded by family members and their support system as unnecessary. (Indeed, the belief both in dominant US society and a number of ethnic groups still remains that many with chronic illnesses or disabilities will always be dependent and cannot be educated or live independently.) In many societies, the roles given to disabled individuals outside the home may be severely restricted; and parents may lose face or be severely criticized by family and friends from within the community if they were to be so heartless as to make their significantly disabled child work rather than caring for them at home.

Furthermore, certain cultural practices and value systems within ethnic or minority groups must be understood, even if the practices and values are not those with which the dominant culture feels comfortable. For example, a gender bias in favor of male children is found in many cultures. A Chinese or Indian family may be willing to go to great lengths to obtain expert medical care or arrange for a solid education for a disabled son. Daughters, on the other hand, are often considered a poor financial risk, and disabled daughters, doubly so. Far fewer resources and much less attention may be given to girls and young women with chronic illness or a disability in traditional families. This does not mean that these children are not loved—it is simply perceived culturally as less justifiable to expend vast amounts of the family's resources on them.

Lack of formal education and occupational training should also not obscure the fact that disabled individuals master many skills and often contribute significantly to their households and family units. Indeed, there are probably few families which can afford to allow any but those with the most severe disability to remain idle. Child care, housekeeping, cooking, and cleaning done by disabled children and adults frequently make important contributions to the overall functioning of the family unit. Hence, a family's reluctance to educate or train a disabled child or encourage a disabled adult to work outside the home may have economic as well as social implications.

REDESIGNING US SYSTEMS TO BETTER SERVE A MULTICULTURAL POPULATION

At a broader level it is clearly impossible to understand chronic illness or disability in a multicultural society without more fully understanding some of the basic and long-identified issues in cross-cultural communication and the immigrant and minority experience. An extensive literature already documents many of the issues encountered when different eth-

*Interestingly, there was an unexpected addendum to this. Several of the same parents who welcomed the birth of a disabled child as God's will, voiced great annoyance not at their physicians, but at their clergy. Strong Catholics, they had fully accepted the Church's explanation that God Himself had assigned them their particular child, but were dismayed to learn their local priests knew little about disability. Many voiced great concern that some of their clergy carried the same misunderstandings and prejudices toward disability as the rest of society. Apparently, the parents feel that the clergy, whom they believe to be God's representatives here on earth, were failing in their role to provide a link to God and in passing along His further instructions and intentions for their children.

nic and minority groups must be served by social, medical, and education systems that do not have some ability to be flexible in light of differing sociocultural needs.[1,2] A key issue in all of this is to remember that the standard US systems, laws, and approaches to serving children and adults with chronic illness and disability are not culture-free. They are unique products of the history and social fabric of the United States.

For example, both in law and in practice within US society, the father and mother of a chronically ill or disabled child will be asked to make the final decisions concerning that child's care and education. The nuclear family is the pattern we consider normal and upon which most of our programs are designed. However, cross-culturally, the nuclear family is a rarity; in fact, only 6% of the world's societies are families as isolated and nuclear as they are in the United States today. The extended family is far more universally the norm.

In societies where the extended family is the norm, parents, particularly young parents, are considered far too inexperienced to make major decisions on behalf of their child and key decisions are made in consultation with older relatives, grandparents, uncles and aunts, and/or a more distant cousin if that individual is considered the head of the family. Not only are decisions made within a larger extended family unit, but much of the actual care, assistance, and emotional and financial support received will come from this extended family network as well.

While US law and custom without doubt will ensure that parents retain the right to make decisions on behalf of their child—and competent adults with a chronic illness or disability to make decisions on their own behalf—it would behoove service providers and advocacy groups to make allowances for extended as well as alternative family systems. Often, in an attempt to empower parents, clinicians, counselors, and educators have refused to include grandparents, cousins, or significant others who have accompanied parent(s) to conferences where a child's case is to be discussed. The assumption that such participation by "outsiders" is disruptive may not be valid. Indeed, parents may not be able to come to a final decision until others have been consulted, and parental requests for others to be included on such occasions should be respected.

Societies may differ not only in the central role played by families, but also in the way they are structured hierarchically. In many parts of the world distinct lines are drawn between members of society based on family connections, education, and wealth, and all members of the society are keenly aware of where they fit within this hierarchy. Professionals such as physicians and nurses, teachers, and social workers are often at the upper end of the hierarchy and their word carries great weight. In such environments a professional asking a patient whether a particular course of action is acceptable will be met with confusion. Such a question may be virtually meaningless within their frame of reference. In many cultures, professionals are presumed to know the answers, and asking for feedback indicates a lack of knowledge or training in the professional. Under such circumstances, when such parents are asked whether they approve of a particular course of action, their answer will almost invariably be a polite "yes." The patients and families who agree in such situations do not always intend to comply, and the frustration felt by professionals who struggle to set up services only to have patients and clients disappear or become lost to follow-up is significant *and* predictable from a cross-cultural perspective.

In societies that have strong social hierarchies, service providers' lives are also complicated by attempts to serve individuals who in the country of origin would be above them on the social ladder. Individuals who have grown up in families of wealth and power within some societies may be difficult to work with, for they may view all who must go out to work for their livelihoods, including professionals, as clearly below the top of the social ladder. In this case, the physician, nurse, or social worker may be treated as hired help. Many professionals can recount stories of individuals who have refused advice, suggestions, or care while vociferously demanding to speak with the "top man" (rarely the top woman) and insisting that they be served first and best. This approach often comes as an eye-opener for professionals in the United States, who are usually treated with more respect, and has made for heated confrontations on many a hospital ward and in many a social service agency. In such situations, culture is, in large measure, to blame. The demanding, elite foreigner is often simply assuming that a hierarchical system of privilege similar to the one with which he or she is familiar also exists in the United States.

Even some of the most fundamental of American beliefs and values, such as individual choice and independence, do not necessarily translate cross-culturally. For example, a family which had recently immigrated from southern Italy reacted strongly (and negatively) to the suggestion that their 22-year-old retarded daughter move into a nearby group home. No amount of discussion of the advantages and independence their child would enjoy could persuade them. Further discussion revealed the cause: traditionally, no proper Italian girl in their social circles lived alone until she was married. The daughter's retardation was thus regarded as irrelevant, a contention strongly supported by the presence of two older, college-educated daughters, also living under the same rules.

Some issues considered key to serving chronically ill and disabled individuals in this country may not be as relevant within some ethnic and minority groups. Education and issues of evaluation through testing provide relevant examples. A complex battery of tests have been developed over the past 50 years in this country by well-intentioned middle-class and upper middle-class professionals for whom education has been very important in their own lives and the lives of their children. Such formal academic accomplishments may be of far less concern to many parents (although the long-term benefits of encouraging any child, where possible, to receive a good education and to become self-supporting is, we be-

lieve, important). At a recently observed school conference called by teachers of a mildly retarded, mainstreamed 10-year-old girl, her Puerto Rican mother was solemnly told that the child would be unable to compete in regular high school and, of course, would be unable to go on to higher education. The mother looked blankly at the team of experts and said: "I never finished eighth grade and I've done alright." She then expanded on her first statement by explaining that she wanted her daughter to find a nice boy: "She's kind of pretty, and she likes babies; I think she'll make a good mom."

Issues are not confined simply to differing perceptions of medical, educational, and social supports. The very understanding and expectations of child development may vary. A cross-cultural knowledge is needed, even when one is called upon to assess a child's physical, mental, and psychological development, for even here, culture does make a difference and an awareness of the expectations and experiences of a child within its own cultural environment is crucial.

In children, the expectations for physical self-sufficiency may vary markedly. The age of many childhood phases is based, in part, on social as well as physiological issues. For example, cross-culturally, toileting skills may vary widely (some cultures beginning as early as 4 to 6 months, some as late as 4 years). Toddlers may not be as adept at crawling if they are regularly carried or in feeding themselves if they are always fed by an adult. In some societies infants and toddlers are rarely separated from their mothers and may cry and carry on "inappropriately" when separated, especially if a stranger is nearby. Physical autonomy is viewed very differently in such societies than in the United States, where middle-class norms dictate that even newborns are often kept in separate rooms, far down the hall from their parents. (In some cultures, "abandoning" a baby in such a manner is considered abusive.) Conversely, some cultures stress autonomy.

In many societies, children are supposed to be seen and not heard, and children are encouraged to be shy with all adults, or all adults outside their immediate families. Trying to treat or evaluate such children using standard white, middle-class norms, where behaviors such as speaking assertively in front of grown-ups and looking adults squarely in the eye are valued traits, can be very misleading. Indeed, in the majority of the world's cultures, assertive children who stare directly into an adult's eye while answering them are simply considered rude.

It is important to determine whether a child-rearing practice is unique (and possibly limiting) to a disabled child, or whether it is the cultural norm for all children. Whenever in doubt, a good rule is to compare the treatment a disabled or chronically ill child receives to that of a nondisabled child of the same age and sex, whose parents have similar social, economic, and sociocultural backgrounds. For example, the coordinator of a program for disabled children recently complained that a Puerto Rican mother of a toddler with cerebral palsy continued to spoon-feed her child, despite repeated insistence on the part of the staff that the child learn to feed himself. The coordinator and the staff feared the mother was coddling a disabled child and fostering an inappropriate dependency. On further inquiry, however, it became clear that the issue was not the child's disability. Many 2-year-old Puerto Rican children continue to be spoon-fed by their mothers months after their white middle-class cohorts have stopped. Such care, in Puerto Rican eyes, is simply part of being a good parent.

No matter what the particular culture involved, it is important to underscore the fact that children from all societies master the full range of developmental skills needed by the time they finish their pre-school years. We live in a society where the medical and intellectual assessment of such children is often based on finely graded differences in development. However, evaluating children from culturally distinct backgrounds must be done with added caution.

Immigrant status adds to and may intensify some of these issues. Psychological stress, linguistic differences, changing personal and familial values, changing role expectations, and (often) lowered socioeconomic conditions all take their toll. For those immigrants who are here illegally, the fear of being sent back makes many reluctant—or extremely fearful—to come forward to request services for disabled family members. The fear of being sent back to chaotic economic or political situations can only be compounded by the fact that their native countries may well have no services available for their disabled family members.

Particularly among more recent immigrants, a long-standing fear of any government agency or hierarchy may make contact and assessment all but impossible. For such families, even the prospect of having a child separated from the parents for an overnight hospital stay may be refused by parents who have lost children in the past. Recently, a Southeast Asian mother became hysterical when her year-old daughter was taken out of the hospital room by a nurse to obtain urine samples. Unable to speak the language and fearing all authority, the mother believed her daughter would simply disappear. The staff, none of whom had any multicultural training, felt her reaction completely inappropriate. In fact, in light of her previous experiences, it was probably not. Three of her older children had been taken "briefly" from her for a work detail in Cambodia. None had returned.

The psychological and physical stress, and in some cases torture through which many of our new (as well as old) immigrants have passed before coming to this country, as well as stressful and often discriminatory experiences while in the United States, are unknown and unappreciated by all too many Americans, including many of those working in the medical and service delivery field. Immigrant parents need clear explanation, whenever possible in their native language, as to what will be done with their child and the reasoning behind it, thus allowing them to participate and make decisions on their child's behalf.

CHANGES IN TRADITIONAL BELIEF SYSTEMS

That a system of beliefs already exists does not imply that new information cannot be provided or that change will not occur. Traditional belief systems on disability have at times proved to be quite adaptive, shifting in response to social, economic, and educational experiences gained during the acculturation process.

When traditional beliefs are discussed, an issue that cannot be avoided is whether change should be fostered. With almost missionary zeal, some professionals and advocates insist that minority groups—particularly those new to the United States—be convinced of the scientific validity of current ideas and approaches. Such educational attempts are often frustrating and unproductive for all involved, for they beg the question of whether members of an ethnic or minority group would be willing to abandon their traditional belief systems.

This approach may also neglect to consider how functional and positive some traditional beliefs and practices are. In many ethnic and minority groups there is a tradition of strong community support for the child or adult with disability and his or her family. In such cases, it may be far wiser and more efficient to build on the strengths already demonstrated by these traditions.

Moreover, how each ethnic and minority group chooses to handle disability within its own ranks is, in part, its own decision. However, while traditional beliefs should be respected and community must always have a voice in the decisions made, we would strongly argue that in those instances where traditional beliefs about disability deny individuals their basic civil and human rights, changes can and should be advocated. Professionals can play a key role here by providing both individuals and families with the most accurate and timely information available, so that they can make informed decisions. However, the most productive on going change within ethnic and minority belief systems will, we suspect, come about internally, through the empowerment of individuals with chronic illness and disability who are members of these particular communities.

ASSESSING SOCIAL ATTITUDES TOWARD CHRONIC ILLNESS AND DISABILITY CROSS-CULTURALLY

Everyone has a cultural heritage that influences his or her health beliefs and practices. It is thus not practical to learn in detail the infinite details of specific cultures, but rather to assume that such variations occur and learn how they might affect one's health practices.[7] Rather than teaching every health practitioner to be a mini-medical anthropologist, it is more important for practitioners to be sensitive to the patient's heritage, to their own heritage, and to what happens when different heritages and belief systems come together.

US professionals are not only members of the dominant medical culture, but they also share the cultural identity of other racial, ethnic, religious, and gender groups.[8,9] As such, they may also hold the prejudices and biases of their groups.

How then does one determine the attitudes toward chronic illness and disability, as well as attitudes toward medical care and other social services found within the particular ethnic or minority community with which one is working? When possible, discussion with individuals and families from these ethnic and minority groups who are already involved with issues of chronic illness and disability is a good place to start. The adult with a chronic illness or disability, not surprisingly, is often most aware of the strengths and limitations displayed by his or her own community's particular response to impairments and will be best able to identify how this may or may not articulate with attitudes in the broader society. Schoolteachers, religious leaders, elders, and traditional healers can provide further information on cultural and community attitudes and responses.

Professionals in our society are trained to obtain information by reviewing the literature; however, a direct approach, particularly in the case where little has yet been written, is often far more profitable. For example, a pediatrician recently recounted the efforts she had made in searching Medline to find information on Mexican attitudes toward the mentally retarded child, and she admitted to being frustrated over the lack of critical literature on the subject. She had overlooked her Mexican-American nurse, her Mexican-American secretary, and five Mexican-American cafeteria workers whom she saw daily in the hospital, all of whom, when asked, had insightful things to say on the issue.

Consulting members of a particular ethnic or minority group may prove to be valuable when trying to determine whether a particular individual's choices and actions are the result of cultural differences or true pathology.[10–13] It is possible to dismiss potentially serious social and psychological reactions of an individual from another ethnic or minority group as simply being the result of cultural differences, when in fact the individual may be in need of direct and immediate assistance. It is also quite possible that an individual may display evidence of both cultural differences *and* individual distress. All cultures have customary ways for individuals to display grief, fear, concern, and disagreement. When an individual's actions exceed the customary limits, all societies designate such actions as inappropriate. In such situations, consulting with others from the same cultural heritage can prove to be extremely helpful in clarifying the situation. As in the case of all other patients, even in such situations, the right of a patient or client to privacy must be respected. As ethnic and minority communities are often small and closely connected, protecting the privacy of an individual, even when others in their community are called upon for input, is essential.

It is also important to note that when very traditional beliefs are at issue, those who most directly participate in the local community are often the best informed. An ethnic or minority group's prominent citizens may be better educated and more acculturated than many others in their community, and hence be unaware of, or far more ready to dismiss, traditional folk belief systems. For example, a French-

educated, professional Haitian recently spent a good part of a morning convincing the social service staff of his local hospital that voodoo is something that Hollywood has made up about his fellow islanders. The same afternoon, a Haitian mother arrived at the clinic with a toddler with cerebral palsy festooned with amulets.

Acculturation ranges across a broad continuum, and determining an individual's or a family's belief systems and social structure must be done on a case-by-case basis. No one can simply assume on the basis of a person's cultural heritage, dress, or language what his or her individual ideas or understandings may be.[14,15] Nonetheless, it is important to remember that traditional attitudes about disability may hang on long after other cultural beliefs are gone, although more acculturated individuals may be sophisticated enough to know that publicly expressing beliefs, such as the presence of witchcraft, is unacceptable.

SUMMARY

To gain at least an initial understanding of the underlying beliefs and attitudes in a cross-cultural situation, we believe that the three key points discussed in this paper should prove a significant point of departure:

1. Traditional beliefs about the cause of chronic illness or disability will play a significant role in determining family and community attitudes toward individuals with a disability and will influence when, how, and why medical input is sought.
2. The expectation of survival on the part of parents and community will have an effect on the amount of time, energy, and cooperation shown by family and community for the individual who has an impairment.[16]
3. The expectations by family and community for the social role(s) an individual with a chronic illness or disability will hold will affect a broad range of issues, including education, social integration, and independence.

Furthermore, although chronic illness and disability are often considered as issues distinct from the full range of problems encountered in society for immigrant and minority groups, in fact, these issues could not be more closely tied. The frequently discussed concerns within the ethnic and minority community about the role of the family, integration and acculturation, social articulation with the greater American society, stress, cross-cultural misunderstanding, and outright prejudice can all compound the problems encountered for the chronically ill or disabled individual in a multicultural society.

CONCLUSION

Ultimately, it will be the members of these ethnic communities themselves and the chronically ill and disabled members of their own communities who will have the final say in how the old and new concepts are integrated or redefined. Not only should up-to-date information on chronic illness and disability be provided to these families and communities, but it behooves program providers to continue to monitor how new information and ideas are integrated into the established community belief system. It is our obligation to provide them with as much information and insight as we can muster, and it is their right to interpret these ideas in light of their own beliefs and concerns. No one individual can anticipate all the problems that might arise in an attempt to understand chronic illness and disability in a multicultural society, but we can all have enough sensitivity to realize that there might be significant differences, and enough respect for others to ask questions and listen carefully to the replies.

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Culture, Ethnicity, and Bicultural Competence: Implications for Children With Chronic Illness and Disability

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The examination of culture and child and human development is not a new venture. There has been a fascination with how culture shapes human behavior over decades.[1–4] Generally, whenever the terms "culture" and "child development" were invoked, they referred to work that was conducted in faraway places and compared to middle-class European-American children and families as the standard or norm.

For so long, studies of development focused on the *generic* human child—white and middle class. LeVine[5] noted that many psychologists seemed to have a deep-seated metaphysical conviction that humans everywhere, all those that counted, at least, were the same in all respects. Cultural variations were merely external details not unlike malnutrition. Importantly, to the discipline's credit, views of child development have changed from the examination of development via a perspective that implied that the human organism existed in a vacuum without context, to the recognition that our understanding of the complexity of individual development is greatly enhanced by focusing on the child in context. Among developmental psychologists, there is a general consensus that a broad spectrum of maturational factors undergirds human development. Even so, human behavior manifests itself in differentiated arrays across cultural settings.

Rogoff[6] suggests that variability is intrinsic to the developmental process and this variability is structured by those events and conditions within the ecological environs that serve to promote and constrain human endeavor. She notes that ". . . the inherent variations in development that occur with different groups and circumstances are ordered in their own terms, with progress toward developmental goals across the course of life."[6(p30)] It is the nature of these terms that constitutes context for varying developmental directions and renders the search for a single universal goal of development counterproductive. The search, therefore, should involve the examination of the ". . . internal coherence of developmental progress in any group according to the combined local and species structure of goals and processes."[6(p30)]

CULTURE, CONTEXT, AND ETHNICITY

What is culture and why is it important in the calculus of healthy child development? Much of what we know about culture, we have learned from anthropologists. While focusing on various aspects of culture, anthropologists generally agree that culture is the sum total of mores, traditions, and beliefs of how we function, and encompasses other products of human works and thoughts specific to members of an intergenerational group, community, or population.[7] For some, culture is the man-made part of the human environment[8] including not only artifacts but also laws, myths, and special ways of thinking about the social environment. Or, culture is that which embodies the interactions among a people including the possibilities, for example, of variation by class, region, religion, and period which can be attributed to sharing in the tradition of the larger group, whether that group be nation, tribe, or province.[1] Still others[9] have focused on the commonality of communication as a method of identifying cultural groups, noting that these groups are homogenous and speak a mutually understandable dialect, or are univocal. Linton[2] and Lum[10] focused on configurations of learned behavior that are shared contemporaneously and across generations such as ethnic beliefs, ideas and superstitions, customs, skills, and patterns.

In an effort to understand contextual influences on development, psychologists in the United States have examined development across cultural settings. When doing so, however, most of the work employed a monocultural perspective,[11] in which the developmental outcomes of children in varying parts of the world were viewed through the lenses of European-American "culture." Some works[4,6,12] have captured the differentiation between the structure of the child's own development and that of his or her environment.[11] Others have focused on the broad concept of the ecology of child development[13–15] or the ecocultural niche which takes into account the evolution of the context through time.[16] It is now acknowledged that the nature of human activity including goals, actions, circumstances, and thought is a function of both cultural and biological endowment, with individuals actively and purposefully handling problems according to means afforded them.[6] This interest in context and development permits a revisit to development among cultural and ethnic minorities within the United States with lenses not focused on deficits.

Ethnicity and minority status then become important factors for considering their role in influencing developmental outcomes for children in general, and children with disabilities in particular. In the United States, a generalized culture is less palpable than in more homogenous nations. While people in the United States, in one form or another, tend to subscribe to some of the founding principles of the Con-

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stitution, we find the existence of a strata of ethnic groups that share some common threads within the fabric of society, while also holding close, beliefs and practices peculiar to their ethnic group. In the United States, therefore, it is often ethnic differences that serve as advantages *and* obstacles for optimal development for children.

Ethnicity refers to group membership in which the defining feature is the characteristic of shared unique cultural traditions and a heritage that spans across generations.[17] Membership in an ethnic group provides the cultural identity and lens through which the developing child comes to understand and act upon prescribed values, norms, and social behavior within his or her world. It also gives meaning to the child's subjective experiences, a scaffold for interpersonal relationships, form to behavior and activities,[17] and a sense of personal survival in the historical continuity of the group.[18]

INFLUENCE OF CULTURE ON DEVELOPMENT

Identity

While recognizing that culture and ethnicity affect all aspects of the developing child, we have chosen to highlight identity (See Spencer and Markstrom-Adams,[19] for comprehensive review) because we see it, along with biological endowment, as a crucible for healthy development. We then discuss factors that potentially (1) obstruct positive developmental outcomes (ie, racism and poverty) or (2) promote healthy growth and development (ie, bicultural competence). Many suggest that the ego has an important function in identity formation. Spencer and Markstrom-Adams define ego identity as ". . .the attainment of an ever-revised sense of psychological reality that is supported by a social reality."[19(p291)] According to Erikson,[20] the development of identity is a process involving personal reflection and observation of oneself in relation to others. Identity develops through this process of comparing self to others and taking in evaluative judgments about the self from others. In other words, this is a developmental task common to all.

In order for competence and adaptive functioning to manifest itself, the individual is required to engage in the psychosocial task of striving for a sense of unification and cohesiveness in the self. Importantly, this process provides meaning, direction, and purpose.[21] Self-esteem and self-concept are viewed as two components, according to Erikson,[20] that precede in the identity-formation process. Spencer and Markstrom-Adams[19] suggest that for minority-status children, there is an additional overlay of precursors to identity formation that include ethnic and racial identity, ethnic and racial preference, ethnic and racial attitudes, and reference group orientation. They explain that ". . . . the complexity of identity formation may increase as a function of color, behavioral distinctions, language difference, physical characteristics and social stereotypes."[19(p292)] For the dimensions of color and language differences, the socialization efforts required of significant others necessitate different and greater burdens and responsibilities for obtaining a maximum individual-environment fit and thus competent individual life-course outcomes (Fillmore and Britsch, 1988, cited in Spencer and Markstrom-Adams[19]). In other words, we have to attend to the transactional processes that occur between the individual and his/her complex worlds.

Achieving group identity is difficult without consistent guidance of important socializing agents.[22,23] Spencer[23] suggests that barring intervention, the direction for identity for African-American children is toward imbalance. Such interventions may come in the form of providing African-American children with a continual dose of evidence that confirms the worth of their cultural and ethnic heritage as a mechanism of offsetting cultural-identity confusion. African-American children may require an arsenal of "psychosocial wherewithal" to meet the barrage of assaults that the larger society metes out to them. The preponderance of negative stereotypes about minorities is counterproductive to acquiring a solid sense of self. These counteracting interventions and processes are required for other minority-status children as well and may come from parents or may be structurally provided through school curricula. The degree of intervention is dependent upon the status of the group within the larger society. These interventions allow for other developmental processes to proceed within a functional framework.

Ethnic identity is the contextual lens through which the child begins to see self in relation to others. It is also the lens through which the child assesses the opportunity structure for self. It is, further, the crucible for interpreting subjective experiences. In other words, ethnic identity has the potential of providing a conceptual framework for making meaning of the ongoing experience of "fit" between self and the environment. The nexus of minority status membership and ethnic identity creates a life-course challenge for the young developing child, because such groups tend to be denigrated and have unequal access to power and resources within society and fewer opportunity options across a range of areas including education, employment, housing, and health care.[17] There is little information regarding the developmental trajectories for children and youth whose ethnic and racial identity have an additional overlay of disability as an identity component.

In his typology of the status of ethnic minorities, Ogbu[24] highlights the plight of those groups that the labels "caste-like" minorities, groups that were involuntary immigrants and relegated to subordinate status. Ogbu further asserts that other minority groups, which he identifies as autonomous minorities (eg, Jews and Mormons), are not subjected to rigid stratification and therefore experience the opportunity structure differently than those "caste-like" minorities. For autonomous minorities, often the ideology of innate inferiority is absent in the relationship between the majority and minority group. In some cases, they can and do opt to assimilate into the majority group, facilitated by the similarity in physiognomy among the groups.

In contrast, "caste-like" minorities tend to have less political power than other groups, and this limited power is complemented by their economic subordination. For example, often African-Americans who have PhDs, having received their degrees at

prestigious majority institutions, were employed in jobs outside higher education, or only at historically black Institutions, not because they were ill-equipped for the rigors of the entire realm of academic endeavor, but more likely because they were not European-American.[25] Despite efforts through legislation such as the Civil Rights Acts of 1965 and since, with few exceptions, members of "caste-like" minorities continue to have their skills underutilized and are relegated to the least desirable social and occupational roles. Even when there is evidence of success in terms of occupation and prestige, it is not without considerable psychological costs.[26,27] While more evidence needs to be provided to establish Ogbu's assertions about behavioral sequelae associated with the "caste-like" status,[28-30] of significance is his point that the denigrated status of a group may, over time, lead to poor school performance, juvenile delinquency, early childbearing, and poor health behaviors and status.

Race and Racism

"Caste-like" minorities are often racial minorities. While anthropological data suggest that race is not a particularly useful term,[31] it is used in the jargon of politics and the political economy. As such, the term "race" invokes crisp images that govern human behavior. It is the political expression of race, then, that dictates, undergirds, and promotes racism. Deeply rooted in the fabric of this society, and not likely to be uprooted in the near term, racism, we believe, serves as a cultural variant in the United States. Unlike benign ethnocentrism, racism is a ubiquitous phenomenon that undermines the character and spirit of the disparaged group. Accordingly, children culturally and ethnically different from the dominant group are more likely than others to experience insults and assaults on character that permeate interpersonal interactions. These children are subjected to social policies sometimes unwittingly designed to undermine their optimal growth and development.[32] Thus, while race is not acknowledged as a psychological variable, the politically pregnant term "race" bears definite psychological and social meaning as revealed through racism and, thus, affects the development of children and adults, across the life course.

Racism interferes with the normal course of development for those children and adults subjected to it.[26,33,34] Racism precludes options for children of minority status, especially for those identified as "caste-like," and it precludes the ability to function at full capacity by systematically reflecting and producing racial inequalities. Even if an individual's level of education enables him or her to raise his or her social status, it is the nature of opportunity for future adult roles and the noneducational factors in obtaining these roles that shape the education system.[24,28,29] Those who have followed the prescriptions for participating in the pursuit of the "American dream" are often excluded on the basis of race. A recent investigative report on *PrimeTime Live* ("True Colors," September 26, 1991) poignantly displayed how an African-American man with the exact credentials and qualifications as his European-American counterpart was denied access to work, shelter, and equal access to means of transportation.

Racism has effects across an array of settings and situations. On the individual level, the experience of racism often *contributes* to a host of problems such as early foreclosure for academic achievement, early engagement in sexual intercourse and childbearing, delinquency, and drug use, to name a few. At the societal level, racism *costs* us decreased workforce productivity, social unrest, loss of human capital through misspent lives, and national malaise. It further *permits* dysfunction among majority-group children, adolescents, and adults by encouraging unrealistic myopic views of the self and group in relation to broader societal functioning.

Race-related social conditions have put a disproportionate number of minority-status parents under stress and duress.[34] This is evidenced by many children's experiences in schools across the country. Parents often are not able to provide the kind of developmental experiences that promote school success or elicit positive responses from others in the larger society. As is customary for most parents, ethnic minority families emphasize certain skills attendant to mainstream success only if these skills lead to success in school, and success in school leads to rewards in adult life such as jobs, income, and prestige.[35] If children of minority status are accorded disrespect and foreclosed options in life, one can only imagine the prospects for minority-status children with chronic and disabling conditions as their health status may be exacerbated by race and ethnicity.

Poverty and Developmental Outcomes

The significance of race underscores class distinctions. Just as racism is a cultural variant, poverty is a structural variable in the lives of ethnic and cultural minorities that takes on social and psychological meaning. It is an insidious form of violence that wreaks havoc on the lives of children.[36] Disproportionately, ethnic and cultural minorities are poor. Among children, approximately 44% of African-American children, and more than 36% of Hispanic children, live in poverty as compared to 15% of European-American children.[37] For parents, fewer resources often translate into fewer psychological resources for child rearing and nurturing socialization.[38-42] Poverty precludes a host of experiences for children including proper nutrition, adequate housing, good education, and access to appropriate and effective health care. These societal deficits serve to produce individuals ill-equipped to meet the challenging imperatives of the broader society. Poor children are unprepared for the demands of school, even starting with kindergarten and first grade.[43] To illustrate more specifically, poor children who are also of minority status are less likely to have access to systems that may promote well-being through good responsive schools. Good, effective teachers are less likely to work in poorly resourced districts; those teachers in schools with high percentages of minority-status poor children often tend to be less motivated to believe in and encourage their students to do their best.[32]

It is no less the case for the health and the medical professions. Poverty is a penetrating and ubiquitous exacerbator of illness and disability. Poor children are at greater risk of death, disease, disability, and injury and experience frequent and more health problems than their economically advantaged counterparts.[43] Poor minority-status children, as compared to more advantaged children, are less likely to have access to effective and responsive medical care, are less likely to experience preventive care, and are more likely to encounter diseases and conditions such as polio, hepatitis, abscessed gums, measles, and whooping cough.[32] While some of these conditions ravage the bodies and minds of hundreds of children, often, they are nonetheless considered among more affluent groups as ones that reside in the historical annals of medicine. How these structural inequalities affect medical practice and outcomes are discussed more fully later in this article.

ACCULTURATION AND BICULTURAL FUNCTIONING

As there is some confusion regarding acculturation and bicultural functioning, we will examine these notions as they relate to the scope of this paper. Acculturation refers to the taking on of values, beliefs, language, customs, and mannerisms of the larger society. Often, it is a process seen among immigrant groups that come to this country in search of a "better life." Historically, they have been more likely to engage in activities that facilitate acculturation. Inherent in the term acculturation is the notion that the individual or group, by taking on the norms of the majority culture, is shedding a culture or those aspects of a culture that are viewed as deficient, inferior, primitive, or dysfunctional.[10] In contrast, according to Ogbu[24] those "caste-like" minorities, due to their perception of opportunities afforded them by society, as a group, tend to be less motivated to shed the vestiges of their heritage in order to achieve a better life. These differences shape how much belief systems will be held onto even in the face of dire circumstances and potential outcomes. Ogbu[28,29] suggests that these differences in status help to promote subcultural behavior patterns that lead to even further dislocation of the self within the larger society. In both cases, the response is one of reactivity and, thus, does not facilitate stable, integrated, psychological functioning for the human organism.

What is bicultural competence? It is our belief that individuals are competent biculturally when they can traverse two cultures with varying distinctive characteristics, tasks, belief systems, and norms. What is important for us is how the individual engages those cultures. We suggest that bicultural competence requires that the individual embrace one culture and acknowledge the other's norms and developmental tasks as requisites for effective functioning within the broader context of society. An African-American who is biculturally competent, for example, may exhibit either of the following: he/she embraces characteristics and norms peculiar to the African-American community while accepting and using practices and ways of behaving in certain situations as mechanisms for facilitating "mainstream" success; or he/she embraces the dominant culture's norms, belief systems, and the like, while identifying with critical aspects of the ethos of the African-American community.[23,44] Being grounded in one specific cultural frame allows the individual to learn more freely new or different cultural systems and to call upon skills to fit the situation.[45] In order for bicultural competence to be manifest, however, the dominant culture has to be viewed as complementing, rather than competing with, the "home" culture.[6] Pragmatically, bicultural competence minimizes dissonance and reactivity; the individual does not eschew completely the prescriptions of one culture over the other. Bicultural competence affords a wider repertoire of behaviors that, in turn, promotes advanced social developmental functioning. If achieved, it sustains individual identity and frees up psychic energy for the pursuit of tangible measures of healthy adaptation and functioning.[27]

CULTURE, ETHNICITY, AND THE DELIVERY OF MEDICAL AND SOCIAL SERVICES

The intersection of ethnicity and development is acutely evident in the delivery of health and human services within the United States. In this section, we review the health status of racial and cultural minorities, with particular emphasis on African-Americans, primarily because at the time of this writing, there are more data available for this group than for other minority-status groups. We then examine the relation of health outcomes to service-delivery models in the context of racial, ethnic, and cultural differences. As health processes and outcomes are inextricably connected to overall developmental outcomes, this discussion is central for our understanding of issues confronting culturally and ethnically diverse children and youth with chronic illness and disability.

Racial and cultural minorities, particularly African-Americans, Hispanics, and American Indians, experience less healthy development than their European-American counterparts in practically all phases of the life cycle. Indicators of physical health differences are notable during the start of life. African-American babies and those in low-income families are more likely to die than are European-American babies and those born of more economic advantage.[46] Since 1980, rather than declining, the rate of low birth weight has increased among African-American babies.[37] Other factors such as human immunodeficiency virus infection threaten the health and development of many of these children.[37,47,48] Of note among minority groups is the high incidence of congenital malformations accounting significantly for chronic disease morbidity.[48] Given the foregoing discussion, it is important to reiterate our earlier assertion that identity is paramount for subsequent healthy psychological development. It is therefore fair to conjecture that those children, youth, and adults of minority status who also share the status of disability, or experience chronic illness, may have a disproportionate burden for negotiating healthy ego development as manifest through identity issues including self-esteem and other components of the self system. Hence, this nexus of minority status and lack

of physical health may serve to undermine optimal psychological development over time barring appropriate interventions. Some of those interventions entail modifications in the delivery of services.

Service Delivery

The distribution of, and access to, medical and human services is inequitable,[49] and this inequality is borne disproportionately by those who are poor and members of racial and cultural minorities.[47] While there has been an improvement in access to medical care for African-Americans since the 1960s, they still experience deficient access to care as compared to European-Americans. Several reasons are put forth as explanations, the primary one being the lower ratio of health providers in African-American and low-income communities.[49] With regard to accessing medical care, African-Americans are less likely to utilize medical services, having fewer visits to primary care physicians than European-Americans. The pattern is similar for other racial and cultural minority groups.[50] In a 1986 survey of black and white differences regarding access to medical care,[49] findings suggest that there is a critical disparity in access to health care which has implications for serious unmet medical needs for African-Americans. Nearly 10% of those surveyed cited economic reasons for not pursuing needed medical care and, of those reporting at least one serious or chronic illness, 25% did not have an ambulatory visit in the year preceding the survey. While the survey did not explore cultural differences regarding the approach to health care and health behavior, the authors do conjecture that sociocultural differences may be the underlying causes for these disparities. It is sociocultural difference to which we now turn.

Often when those in the medical and human services professions interact with their patients and clients, they do so with a presumption that as service providers they are the experts. Yet, while they may possess considerable knowledge about disease, conditions, and institutional procedures, the presumed status of "expert" precludes effective treatment outcomes for the population being served.[50] With the exception of following orders, the presumption of expert status does not allow room for the patient/client to actively participate in the process of creating healthy outcomes for self or children. The manner in which expertise is communicated dictates the nature of the relationship between patient and provider. Data indicate that patients who are ethnically and culturally different from the service providers often do not follow through on prescribed medical regimens for themselves or their children. The reasons for such noncompliance phenomenologically are rooted in patients' interpretations of the meaning or significance of their experiences with the providers. In some cases patients believe that the physician or service provider is not really interested in them or their health. Blenden and associates found that blacks were more likely than whites to report "... that during their last visit that their physician did not inquire sufficiently about their pain, did not tell them how long it would take for prescribed medicine to work, did not explain the seriousness of the illness or injury, and did not discuss test or examination findings."[49(p280)] The perception of being provided inadequate and unsatisfactory care often elicits counterproductive behaviors which, in turn, engender more nonsupportive responses from the providers.

Central to this vicious cycle is a lack on the part of the service providers in acknowledging the role a patient/client plays in the health care process. This holds true especially for minority-status parents of children with chronic diseases or disabling conditions.[51] Since many services rendered to minority families are judged ineffectual, attending to their perceived needs and understanding the belief systems of parents from different ethnic groups facilitates more effective health care and health outcomes.[51,52] Why families who are accorded "minority status" do not comply with medical service directions is due, in part, to their perception of being looked down upon or not being acknowledged as legitimate participants in their children's health care. According to Kalyanpur and Rao,[51] many low-income families refer to their relationships with professionals as unempowering. Aspects of these unempowering relationships include disrespect, a focus on deficits, and a discounting of differences in parenting styles.

Cultural, Ethnic, and Class Factors

Cultural sensitivity and affirmation appear to be critical to effective health care. The notion of health is significantly linked to the way in which people construct reality, which often is dictated by culturally defined belief systems and expectations.[52] This construction of reality yields different outcomes that from a traditional provider may appear to defy "reasonable" health or treatment resolutions. For example, because of difficulties in management, institutionalization of profoundly retarded children is often recommended. Among families with severely and profoundly retarded children, however, Spanish-Americans are more likely than are their black or white counterparts to keep their profoundly retarded children at home than in an institution, or they place them in a community setting.[53] It is believed that due to strong family unity, all family members are valued as they are. This belief system obtains for Native Americans as well.[54] Similarly, poor Chinese-American families of children with developmental disabilities often encounter a system of services, practices, and treatments that does not coincide with their own cultural beliefs or perspectives.[50] Due to cultural differences, sometimes the concept encompassing developmental disability is not communicated effectively. Smith and Ryan[50] suggest that there is no concept regarding a developmental disability from the Asian perspective. Whether this is true or not requires more culturally sensitive empirical assessment. What is important is that the lack of communication leads to parents' increased likelihood of attributing blame for their child's condition to fate or to their own bad behavior and misgivings. This, coupled with attendant language barriers, minimizes receiving appropriate care, places the family and child in a web of confusion, and puts the Asian child with developmental disabilities potentially at greater risk across the life course.[50]

Other factors intervene in the process of creating beneficial health outcomes for poor and minority-status families of children with chronic and disabling conditions. Parents of children with disabilities tend to be limited in the power and authority regarding the kinds of services that they need and can procure. This limited authority over their children's lives is exacerbated by their inherent disenfranchised status as a minority.[51] It appears that at the intersection of ethnicity/culture, poverty, and the provision of services for families of children with chronic and disabling conditions, there needs to be a recognition of the interdependence of these factors for positive health-status outcomes for the children. Health care providers, while bringing their knowledge base to the situation, also have to be competent from a multicultural perspective to the extent that they acknowledge the partnership role of parents in those outcomes. The communication of information and the dispensing of care can be enhanced if the provider can possess and exhibit a sensitivity to the cultural attributes of the parents.[52,55–58] In some instances this requires using the cultural notion of health or disease as a mechanism for moving toward the desired outcomes such as compliance. As the improvement of appropriate and effective health status outcomes is the desired goal, we suggest that the proposed transactional model serve as a heuristic and conceptual lens for moving toward that goal.

TRANSACTIONAL MODEL

Taking an ecological perspective to health and development, we can assume that desired outcomes can be approached if the child is viewed within the context from which he/she obtains his/her lens of the world. As seen in the Figure , the creation of positive health status outcomes requires the following recognitions:

- The child is embedded in an array of systems that holds different and sometimes competing sets of phenomenologically based assumptions about how the world is configured, and thus operates.
- Inherent in those sets of assumptions are perceptions of disease, disability, and health, based on experience, training, and/or cultural and ethnic belief systems.
- Interactions among agents in relation to the child produce transactional processes that are either affirming of the child and its family or entail procedures that look for deficits in parent compliance and motivation or within the cultural niche itself.
- The degree to which the health care system is effective is an indirect function of the nature and quality of those transactional processes.
- The child's health status results, in part, through the nexus of its biological substrate and the interacting processes within its ecocultural niche.

CONCLUSION

This paper has addressed in summary fashion the role of culture and ethnicity in developmental outcomes for children. We have attempted to develop a scaffold with which we can begin addressing factors that inhibit and promote effective primary and secondary care for minority-status children with chronic

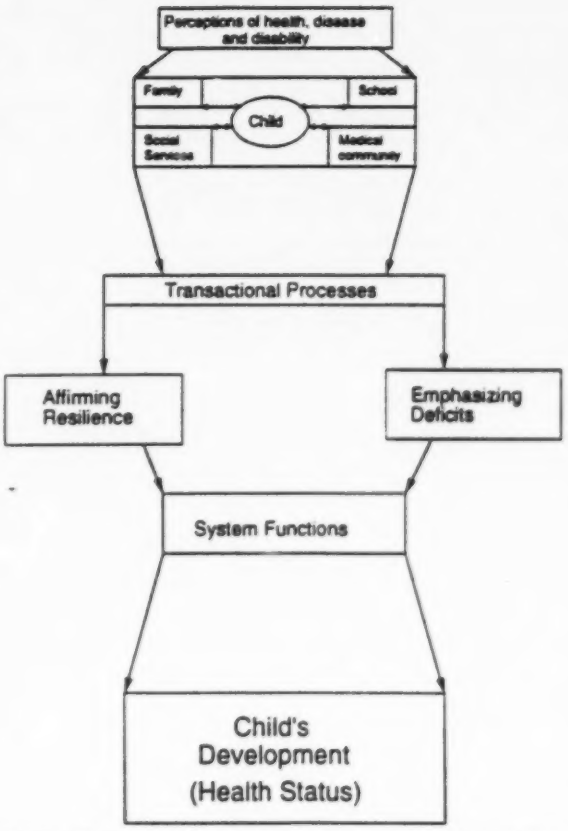

Figure. Transactional model for the creation of health status outcomes.

and disabling conditions. High rates of congenital malformations occur among African-Americans, Hispanics, Asians, and American Indians.[48] Although the kind and severity of malformations vary by race, ethnicity, and social class, a more finely tuned understanding and appreciation of sociocultural nuance potentially will facilitate a decrease in morbidity and mortality, and thus, improved health status across the life course. Issues such as ethnic identity, cultural imperatives, bicultural competence, and racism require open discussion and scrutiny in relation to the health care delivery system as presently constituted. To date, there are few data regarding the course of development for children and youth who are of minority status due to both race or ethnicity and disability. We especially have little information as to how we incorporate ethnic and cultural definitions of, and meanings attached to, disease and disability into appropriate mechanisms for health care provision.[54] These data would assist significantly in developing appropriate and effective health policies and programs for these growing populations. Finally, it is imperative that whatever policies and programs are established, our understanding of normative developmental processes must be central to those undertakings. To the extent that there are few available ecologically sound, normative databases on minority-status children, let alone for those who also have chronic illness and disabilities, there is a need to proceed quickly, yet cautiously, with agendas for pro-

gram and policy development and sound developmental research.

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Culture, Ethnicity, and the Family: Critical Factors in Childhood Chronic Illnesses and Disabilities

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The family has always been implicitly and explicitly recognized as a critical social unit mediating cultural beliefs and traditions from one generation to another. This includes the mediation of beliefs and practices regarding health, illness, and chronic conditions.[1] There is, however, a dearth of research linking cultural and ethnic factors to the ways in which families respond to and cope with childhood illnesses and disabilities, despite the recognition that effective health care practice involves an awareness of the strong, often covert, influence of culture in shaping family reactions and responses to health problems. In fact, cultural and ethnic sensitivity alone is no longer adequate; health care professionals must also be ethnically and culturally competent, that is, be able to recognize, respect, and engage ethnic diversity in a way that leads to mutually desirable outcomes. This expectation for cultural competence is directly related to the ever-growing percentage of ethnic minorities in the United States, particularly the increase in the number of persons of Southeast Asian and Hispanic origin, the increased risk minority status places on child development, and the emerging emphasis on, if not renaissance of, cultural and ethnic identity.

The effectiveness of interactions with families of different cultural backgrounds may well be shaped by pediatricians' and other health care professionals' awareness of and sensitivity to the influence of culture and ethnicity on children's psychosocial development as well as on the family's response to the long-term care of a child with chronic conditions or disabilities. This article attempts to encourage this line of inquiry, first, by identifying the family processes of appraisal focusing on schema and paradigms which are influenced by culture and ethnicity and which appear to come into play in shaping the family's response to the illness or disability; and, second, by focusing on two Native American cultures, aboriginal American Indians and Hawaiians, their cultures' influence on the family system and the family's response to children with chronic illness and disabilities mediated by culture. Thus these two processes, schema and paradigms, become critical targets for intervention and fall within pediatricians' realm of sensitivity and, to some degree, their influence.

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CULTURE AND FAMILY FUNCTIONING

The impact of culture on family life has been documented in the literature of family studies. The comprehensive review by Tseng and Hsu[1] reveals that over time culture has influenced family functioning in a great variety of ways: marriage forms, choice of mates, postmarital residence, the family kinship system and descent groups, household and family structures, the primary axis of family obligations, family-community dynamics, and alternative family formations.[2–16] Historically, the family has been the conduit for cultural transmission, providing a natural atmosphere for traditions to be passed from generation to generation, as well as updated throughout the ages to keep culture and ethnic heritages alive. In turn, the traditions themselves have given families a sense of stability and support from which they draw comfort, guidance, and a means of coping with the problems of daily life.

A cursory review of the literature of chronic childhood illness across ethnic groups reveals a meaningful but rather stereotypic list of descriptions of family values and patterns of functioning, such as having "strong ties with extended families," and the "practice of tribal customs and traditions."[17] Although they have not rendered clarity to the interacting influences of culture and the family, these stereotypes have served a useful function of pointing to the importance of cultural differences and revealing the profound variability that exists even within cultural groups. Efforts to homogenize ethnic groups, both in research and descriptive accounts, contribute to stereotyping and reinforce the current practice of oversimplification and using broad descriptive categories to encompass, and thereby mask, the variability within ethnic groups. Dependence upon stereotypes is strengthened by the absence of research that attempts to understand within-group diversity, such as the difference between the experiences and values of *immigrant* ethnic groups and those of *aboriginal* ethnic groups. A case in point: national studies of ethnic families continue to group Asian and Pacific Islanders as a major demographic category even though Asian-Americans are largely immigrants and Pacific Islanders are primarily aboriginal, Native Americans. Another example is the Asian-American category, which includes Japanese, Chinese, and Koreans and is too broad to render clarity to cultural differences and uniqueness.

Within the medical community, the importance of culture, ethnicity, and the family has long been rec-

ognized in the diagnosis of specific illnesses and conditions.[18,19] Medical professionals are aware of the genetic and sociological connections between certain ethnic groups and higher incidence of certain illnesses; sickle cell anemia is more prevalent among African-Americans, and fetal alcohol syndrome is higher among Native Americans.[20] Yet, while culture and ethnicity have been used by medical professionals to make predictions about the distribution of illnesses, the impact of ethnicity and culture on the family's response to illness has not received the attention it deserves.

In assessing the adaptation of the family system to a chronic illness or a disability, the medical community has tended to apply Anglo-American perceptions of disability to all families, including those of ethnic minorities. The unspoken assumption has been that the existence of common symptoms would lead to similar family reactions regardless of the ethnic or cultural associations of the patient's family.[21] When ethnicity has been considered, the tendency among practitioners has been to accept global assumptions of all ethnic groups without exploring the diverse aspects of culture that shape family problem-solving and adaptation.

We have attempted to address these issues here, by drawing from the limited literature on two aboriginal groups: Native American Indians, particularly the Navajo, and Native Hawaiians. In focusing on these two groups, we can begin to shed light upon which culturally relevant values and behaviors appear to shape the family's responses to children with chronic illness and disability. In turn, we can begin to understand the mediating influence of the family system's appraisal processes involving family schema and paradigms in adapting to the stress of childhood chronic conditions.

In an effort to minimize stereotypic global assumptions about ethnicity and culture, we chose these two groups of Native Americans, not only to illustrate cultural variation, but also to highlight their basic similarities, including aboriginal status, being colonized by nonnative groups, and the apparent resiliency of their native cultures to adversity. Additionally, many Native Hawaiians and Native American Indians, referred to together in this article as the *Aboriginal Cluster*, are striving for greater political recognition of sovereignty and a rejuvenation of their cultural heritages through major cultural renaissance initiatives. In examining the relationships between ethnicity and family coping with chronic illness and disability, the Native Hawaiians and Native American Indians are also similar in that each has a high risk for certain diseases. Native Hawaiians have higher death rates for heart disease, cancer, stroke, and diabetes than nonnatives.[22] Likewise, the increased incidence of alcohol-related illnesses, diabetes, gallbladder disease and obesity among Native American Indians has been acknowledged by the medical community.[23,24] For this article, it is also significant that both of these aboriginal populations place central cultural emphasis on the family as a mediator of culture and as a critical social agent through which medical treatment and long-term care are provided.[25–27]

APPRAISAL PROCESSES OF FAMILY ADAPTATION: INFLUENCE OF ETHNICITY AND CULTURE

Both ethnicity and culture, used similarly in this article, are defined as the customary beliefs, integrated patterns of human behavior (eg, thought, speech, action), social forms, and traits of a racial group. They are nurtured, cultivated, and transferred across generations and among family members through traditions and celebrations, as well as through family problem-solving efforts.[28] In solving problems and managing family life when a child has a chronic illness or disability, the family's culture fundamentally influences two critical levels of family appraisal involved in the process of adaptation: the family's schema and paradigms.[29,30] These processes of family life are the way in which families give "meaning" to having a chronically ill child, and they appear to play a fundamental role in shaping the family's responses and strategies for initial and follow-up medical care and treatment.

Family Appraisal Process: Family Schema and Paradigms

The concept of family schema, so important in processes of appraisal, may be traced to the general literature on the psychology of stigma, which underscores the critical importance of ethnicity and culture.[31–33] A family schema may be defined as a structure of fundamental convictions and values shaped and adopted by the family system over time, which creates the family's *unique character* and serves as an overriding shared informational framework against and through which family experiences are processed and evaluated. A family schema, which is expressed through the family's "world view," encompasses cultural and ethnic beliefs and values and evolves into an encapsulation of experience that serves as a framework for evaluating incoming stimuli and experiences.[34,35] A family schema, which is highly resistant to change, could include values such as respecting and maintaining one's ethnic heritage and honoring and respecting one's elders; it might include convictions such as making a commitment to the education of one's children even if it means a personal sacrifice for family members, fostering independence for all members, having and maintaining open family communication, and sharing an unwavering commitment to the care of children and commitment to the preservation of the family unit. Not only does a family's schema give some order and stability to family life and is shaped by the influence of culture and ethnicity through the mediating process of family paradigms, it plays an influential role in shaping the family's responses to chronic illness or disability. Through this second-level family process of creating, maintaining, and changing paradigms, families also determine the specific problem-solving and coping strategies that are part of adaptation to the crisis of childhood chronic illness and disabilities.[36]

The concept of family paradigms,[37] defined as the family's *specific* set of beliefs and expectations (eg, the use of tribal methods of treatment; the expectation that they work as a family unit to solve problems) is used to guide the family's patterns of functioning affecting *specific* domains of family life (eg, the domains of the marital relationship, child rearing, intergenerational relationships, health care and treatment, sibling relationships, work roles, education, definition and treatment of chronically ill and disabled members). In the context of a family's schema, family paradigms develop to guide the day-to-day care and management of family life. Paradigms serve as a family framework intended to create, guide, change, affirm, and legitimate family behaviors and patterns of functioning.[38] Family paradigms concerning the care of a chronically ill or disabled member may include a belief in an unconditional acceptance of the child accompanied by the expectation that all members will contribute to providing care, the belief in the importance of tribal methods for treating illnesses and the expectation that the health care system will allow and respect their "methods," and the belief in their definition of the family, which includes relatives and close friends and which is accompanied by their expectation that health care professionals will respect and affirm their "being part of the family." Within this family paradigm, grandparents' involvement in care and decision-making may be as important as the use of medical specialists and highly specialized medical centers or institutions.

The meaningful relationship between family schema and paradigms may be described by using the metaphor of a simple umbrella intended to provide protection, in this case to help a family unit cope with stress. At the top, the center of the umbrella is the hub, the family schema consisting of its shared and fundamental values and convictions. Emanating from the hub are a series of ribs, or spokes, each with a specific purpose designed to define and bring breadth, balance, and stability to the umbrella. These spokes may be viewed as family paradigms designed to guide different aspects of family life—the marital relationship, parenting, work and family, intergenerational relationships, and health care. Each is linked to the hub, but each has a unique purpose in guiding and supporting family coping and functioning. To complete the metaphor, the umbrella, characterized as the family's appraisal process, is designed to provide protection to the family system, particularly during periods of adversity and inclement conditions.

Once a paradigm is shaped and adopted by the family system, family behaviors will then be guided, if not governed, by that paradigm or successive paradigms. Once a paradigm is used to interpret phenomena and to guide family behavior (eg, a traditional family paradigm with mother working "full time" in the child caretaking role), the family will never function in the absence of some paradigm. Concomitantly, for a family unit to reject a paradigm that has served to shape a domain of family life without simultaneously substituting another (eg, an egalitarian family paradigm with shared roles and responsibilities in child care) is to reject the nature of family functioning itself. Once shaped, adopted, and employed to guide family behavior, family paradigms will be maintained and upheld as long as they are successful for the family unit. Family paradigms are not likely to be doubted until the family faces a crisis that places the family's paradigm in question, whereupon alternative paradigms are considered and tested for congruency with the family's schema and for efficacy in shaping patterns of functioning that would be helpful in achieving a satisfactory level of family adaptation in the face of the crisis.

It is our perspective that family paradigms are influenced by the ethnic and cultural heritage and teaching of family members, which have already been incorporated into a family's schema. Ultimately, culture and ethnicity shape paradigms for family functioning, particularly in the crisis situations in which the family's stability and continuity may be threatened. To further this reasoning, we can begin to describe the integration of culture into the family schema and paradigms by drawing from the literature on Native American Indians and Native Hawaiians, the Aboriginal Cluster.

Cultural Factors and the Family Schema

To illustrate the role of ethnicity and culture in shaping a family's schema, we describe the Aboriginal Cluster, and contrast them with Anglo-Americans on five components of family schema.[39,40] The family's schema includes shared values and convictions regarding family structure, self or group concept, spiritual beliefs, nature and the land, and time orientation (see Table 1). Specifically, the Aboriginal Cluster emphasizes the extended family structure, or tribal structure in the case of the Native American Indians. They have a common concern for the social and economic well-being of all and have a family network of support that encompasses both immediate and extended family. Generally, the opposite is true of the Anglo-American system, which emphasizes the closed, mutually supportive, nuclear family support system of parents and children. Predictably, the Aboriginal Cluster has developed a "we" group orientation where the needs of the whole rise above the needs of the individual.[41] In the case of Native Hawaiians, the concept of *malama*, or caring, is the dominant theme that places the family group as a whole above the individual. Such a view is in sharp contrast to the Anglo-American schema, which underscores the individual or the "I" orientation.

Spiritual-religious underpinnings also play an important role in shaping the family's response to the challenge of long-term care of the child who is chronically ill or disabled. The Aboriginal Cluster views the world in terms of a "Great Spirit"; spirituality is part of the entire world. From the Native Hawaiian perspective, spirits appear in many forms, and the individual strives for unity with the cosmos as the way to achieve spirituality. This is unlike the Anglo-American schema, in which religion and spirituality are compartmentalized and individualized aspects of life, and spirituality is formalized through well-structured and well-delineated religious groups and be-

TABLE 1. Ethnic and Cultural Dimensions of Family Schema or Family World View

Family Values and Convictions	Anglo-American	Aboriginal Cluster	
		Native American Indian	Native American Hawaiian
Family structure	Nuclear family: parents and children	Extended family tribal structure: concern for social and economic well-being for all	Extended family: social support networks
Self/group orientation	"I": individual orientation	"We": group orientation with emphasis on the needs of the group above that of the individual	"We": group orientation with mutual *malama* (caring) more important than the individual
Spiritual beliefs	Individualized, compartmentalized: God is other-worldly	The Great Spirit is in all: spirituality is part of the world	Spirits appear in many forms in the world: individual should strive for spiritual unity with the cosmos
Land/nature	Land is inanimate: environment should be owned, controlled, and used by humans	The environment is living: land should be respected and preserved; what we do to the land we do to ourselves	Land is the basis for *aloha aina* or *aloha malama* (love and care for the land); resources must be nurtured and preserved for future generations
Time orientation	Future-oriented: time must be structured	Present-oriented: time is relative, life is cyclical	Present-oriented: time is relative

liefs. Religion then becomes a source of support to give meaning to life. Conversely, the Aboriginal Cluster sees spirituality as a natural outgrowth of *all* aspects of life. This spiritual orientation to life facilitates the Aboriginal Cluster's ability to create a family paradigm that cultivates the belief that a "disabled" child is "normal" and a "valued" member of the community, despite any physical or developmental handicaps.

The two additional components of family schema which shape family paradigms are nature and land, and time orientation. The Aboriginal Cluster views the environment as living. Land cannot be owned and should be respected and preserved. From their point of view, what we do to the land we do to ourselves. The Native Hawaiian view is that land is the basis for life. *Aloha aina* or *aloha malama* reflects their belief in loving and caring for the land. Resources must be nurtured and preserved for future generations. The Aboriginal Cluster extends the philosophy of harmony with the land to other aspects of life, with emphasis on achieving balance with nature and a sense of wholeness and harmony. By contrast, the Anglo-American schema regarding the land emphasizes that land is inanimate and that the environment should be owned, controlled, and used for productivity and development.

The future-oriented and "timeless" structure of the Anglo-American schema may be contrasted with the Aboriginal Cluster's view of time. From the latter's perspective, time is relative, just as life is cyclical. Native Hawaiians as well as Native American Indians think of time in the present; families do well if they take advantage of the positives and the strengths of the moment. The Anglo-American paradigm, on the other hand, encompasses time with a future-oriented perspective: it must be managed and used effectively.

Culture and Family Paradigms

One's culture and ethnicity have a formative effect on schema-level appraisal, and, whether or not ethnicity is consciously and planfully incorporated into the paradigmatic patterns of family functioning, their effects can be observed.[42,43] In a recent study of Navajo children with autism and their families, it was shown that despite some families' conscious choice to follow a less traditional path and thus define themselves as modern (rejection of ethnically based traditional ways) or semitraditional (living in a nontraditional way, but incorporating some ethnically based traditional ways), the influence of cultural beliefs and definitions of disability had a wide-ranging and powerful effect on the family's paradigm and the family's adaptation to the long-term care of their disabled member.

As depicted in Table 2, the culturally shaped paradigms of childhood chronic illness or disability for Native American Indians and Native Hawaiians are distinct from those paradigms held by Anglo-American families. Although Native American Indian values vary between specific tribes, the overall Native American Indian definition of illness or disability focuses less on the inabilities of the children involved, and centers instead on the function the children, whatever their abilities, can serve within the family and the community.

The wider range of accepted behavior in Navajo culture and their family paradigm, for example, means an individual's function within society is valued regardless of how limited his or her contribution is. "Thus to be able to care for lambs with minimal supervision, to help with chores such as gathering wood or carrying water, to express a flicker of recognition towards a familiar person, and to attempt to communicate through wordless vocalizations or non-verbal gestures, is quite often seen as falling within the broad standards of becoming a socially competent Navajo."[44]

Whereas the Anglo family paradigm may consider disability and illness as foreign and intrusive in the family system, the Native American Indian and Native Hawaiian paradigm stresses the wholeness and harmony of life, of which illness is a part. While an Aboriginal Cluster family faced with a serious dis-

TABLE 2. Ethnic and Cultural Dimensions of Family Paradigms: Specific Beliefs and Expectations

Specific Domains of Family Functioning	Anglo-American	Aboriginal Cluster	
		Native American Indian	Native American Hawaiian
Child rearing	Parent-focused responsibility	Community-focused child rearing: children are to be shared; discipline and nurturing responsibility of all	Community-focused child rearing: each child is a *pua* (flower) representing the future; extended family has major responsibility
Work roles	Work for the future: success demonstrated through wealth	Work for the present: accumulated wealth should be shared with extended family; legitimates and values work roles	Work for the present: work should provide a service or benefit to society: legitimates and values different work roles
Education	Formal education stressed: individual achievement is stressed	Education occurs in all facets of life: individuals should learn from one another	Education is part of the group orientation: learning from one another is more important than individual achievement
Meaning and treatment of chronically ill and disabled members			
Role of disabled	Limited: viewed as different and stigmatized	Viewed as valued, functioning member of the society	Absorbed as valued, functioning members of the society
Source of illness	Scientific cause, outside of family	Introspective: illness or disability may be due to misconduct for which family is being punished; family or kin is responsible	Introspective: illness or disability reflects an imbalance in the *mana* (energy) or *pono* (harmony); family or kin responsible
Definition of illness or disability	Foreign, intrusive	Part of the whole: view illness as part of a more general pattern of harmony disharmony	Illness is part of wellness; normal
Language of disability	Stigmatizing labels	No words in most Native languages to classify disabled: assimilated	No words in Hawaiian language to classify disabled: assimilated
Orientation to treatment	Private and professional with focus on cure	Public: medicine involves ritual and spirituality; aimed at restoration of wholeness and spiritual balance; community/family involvement	Family and community with medicine focused on restoring *pono* (harmony) and wholeness
Problem-solving and accommodation	Individualized and private, with emphasis on professional care	Community-oriented, with emphasis on community acceptance and integration: extended family and tribal social support; emphasis on care of family members	Community acceptance and integration: extended family form protective net around individual: *aloha 'ohana* (love of kin) and *ho oponopono* (ritualized family and kin problem-solving)

ability is forced to process the same information and many of the same reactions of sadness and sorrow experienced by an Anglo-American family, the former's assessment and accommodation of the disability also centers around the restoration of harmony rather than a singularly focused attempt to "cure" or "fix" the disabled child.

Family Meaning of Disability. The Aboriginal Cluster appears to cultivate a family paradigm that gives no "special" meaning to having a child with a chronic illness or disability; the children and their medical conditions are not labeled. Illness and disability are seen as part of a more general world view of wellness and harmony; family members may differ in the degree to which they may be be ill or well, but all members are accepted and valued regardless of their physical condition along the continuum. What the Aboriginal Cluster labels as the source or cause of illness appears to be an extension of their schema. They place responsibility for the child's medical situation upon themselves, as well as upon the natural cycle of life characterized by periods of harmony and disharmony. This paradigm places responsibility for care and treatment of the child upon the family and kin system; harmony can best be achieved through shared family and community efforts. The extended family is emphasized as a source of long-term care. By contrast, for Anglo-Americans, illness and disability are foreign to the family unit, and thus become stigmatizing labels which, in turn, necessitate their receiving "special" treatment. Since the cause for the illness or disability is perceived to lie outside the Anglo-American family unit, the emphasis on medical treatment is likely to become a major strategy for providing ongoing care.

These paradigms about the meaning of disability are supported by two complementary paradigms in the realm of work roles and education. Parental roles in providing care for the children are supported by a paradigm which accentuates the value of providing a service or benefit to society. In contrast to the Anglo-American family system, in the Aboriginal family Cluster, education and learning are not only shared among family members, but experiential learning is highly valued and affirmed. Essentially, family development and functioning in the Aboriginal family Cluster is underscored in the family paradigms of sharing the responsibilities for long-term care among

members and kin, affirming the value of all members and their contributions to the family and its members.

Family Care and Treatment. Clearly, the family's paradigms which give meaning to illness and disability, and which shape the family's development and functioning, interact with the family's paradigm for providing care and treatment. The Aboriginal Cluster of families uses cultural methods to assist the family in restoring harmony and healing, and these methods often include the immediate family and the kin network of relatives and friends in problem solving. Acceptance and incorporation of the ill or disabled member is an underlying goal of the family's efforts to cope with the situation. The Anglo-American culture places a strong emphasis upon private and professional treatment of the chronically ill or disabled member. In this case the family functions as a closed unit, limiting information and care to select persons and professionals.

ETHNICITY, CULTURE, AND CLINICAL PRACTICE

With the added emphasis upon culture and ethnicity in understanding the plight of families caring for members who are chronically ill or disabled, there is a fundamental belief that the family system is a viable target for intervention.[45,46] As Stanton[47] has emphasized, the family unit must be seen as people interacting within a context—both affecting it and being affected by it. Consequently, family-focused interventions assure that family members can change and family paradigms may be modified, thus allowing new behaviors and family patterns of functioning to emerge, if the overall family context is changed.

The ease with which health care professionals incorporate cultural or ethnic factors into their repertoire of interventions and strategies will depend upon several factors: (1) the cultural or ethnic background of the health care professional; (2) the sensitivity and competence of the health care professional to deal with cultural and ethnic factors; (3) the degree of conflict between the family's paradigm for care and treatment and the use of the services of health care professionals; (4) the residual and often asymptomatic influence of racism, poverty, and political powerlessness that accompanies cultural and ethnic consideration; and (5) the critical elements of language, and strength of cultural and ethnic identification.[48,49]

There is a need for practitioners to be conscious of cultural beliefs, values, and perspectives on illness and disability that have significant influence on the perceptions and reactions of families whose responsibility it is to care for a chronically ill or disabled child. Cultural sensitivity and competence to deal with ethnicity can prevent health care professionals from unintentionally alienating parents or families through miscommunication or what the family considers inappropriate and unacceptable suggestions or behavior. Since such misunderstandings could result in the child's receiving inadequate medical attention, particularly if the family feels hesitant about placing trust in someone who so clearly does not understand their values, it is vital that practitioners remain aware of the cultural context within which the family is operating. For example, a direct style of addressing the family and confronting the issues would likely be viewed as noncondescending by Asian-Americans and African-Americans, and conversely may be perceived as rude by Native American Indian families, and threatening by Mexican-Americans.[50]

Similarly, if a suggested treatment conflicts with family cultural or religious beliefs, it may be difficult to convince the family that the physician has the child's best interest in mind. Conflicts may range from a refusal to consent to surgery due to cultural taboos against cutting someone open, to the varying definition of "disabled" across cultures. In the case of disability, if a child's condition does not seem problematic to the family, it is unlikely that they will respond favorably to the notion of treatment; there is no reason to apply a repair process to something that is not broken. For example, a Native American Indian family may reject the removal of a "disabled" child to an institution for care or therapy since they consider that the child functions as perfectly and productively as his/her abilities allow.

It is also important for physicians to understand how their own cultural identity and their own family "paradigms" might affect the reactions of a family or patient, particularly with regard to issues of trust and shared confidences, openness in discussing problems, value placed on the practitioners' medical opinion, and willingness of the family to accept treatment or advice for their child. Reticence in any of these areas is often attributable to the family's paradigms of cultural values or biases and thus should not be taken for ignorance about the problem or lack of concern about the need for a solution.[51]

In *Ethnicity and Health*, Farley[52] argued that because all health care providers are part of diverse and mixed society, it is imperative for all primary care providers to be aware of and responsive to society's diverse cultural heritage. Some have developed a personal insensitivity to patients and, for example, fail to recognize an ethnically based family's paradigm which includes and legitimizes "at home" treatment; a treatment belief system resulting in bruises on a Hmong child from "coining" or "cupping" may be erroneously reported as child abuse. A caring and ethnically sensitive provider who recognizes the family paradigm, and the same clinical symptoms as the result of a culturally related healing system, may respond differently and appropriately.[52]

A practitioner who is aware of the impact of cultural beliefs on a family's schema and ultimately on its paradigms regarding a chronically ill or disabled child is better equipped to approach discussions and suggest treatments in a way that the family finds nonthreatening and acceptable. This, in turn, will foster a trust between the family and the practitioner, which should make the family more willing to implement the physician's suggestions and may even enable the latter to convince the family of the need for certain treatments which, in the beginning, they may have rigorously opposed, or refused.

There are many specific ethnic or cultural practices which practitioners should consider on a situation-by-situation basis, among them: the implications on the family of the suggested treatment, for example, the cultural ramifications of a long-term separation of the child from the parents; the possibility of topics that should not be discussed with a parent who is not of the same gender as the physician; and cultural curative practices that the family may have legitimated in their paradigm and thus prefer over "modern" or "scientific" ones.[53] In the end, however, physician and parent have a common bond: the child's well-being. Thus, for the sake of the child, it behooves practitioners to understand their own prejudices, beliefs, and behavior and how these "fit" or do not "fit" with the family's schema and paradigms. Ethnic sensitivity and competence and family-centered, community-based care require this kind of collaboration and congruency.

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Race and Ethnicity: Issues for Adolescents With Chronic Illnesses and Disabilities. An Annotated Bibliography

Gayle Geber, MPH, and Elizabeth Latts, MSW

CULTURAL COMPETENCE RESOURCES

The following are selected resources providing general information about the issues of cultural competence and cultural diversity. While they are not specific to adolescents with chronic illness or disabilities, these resources are relevant across the age span and contain important information for health care professionals, educators, parents, and program planners.

Asbury CA, Walker S, et al. Disability prevalence and demographic association among race/ethnic minority populations in the United States: implications for the 21st Century

A study that examined the status of ethnic/racial minority persons with chronic health conditions; physical, sensory, and language impairments; and nervous disorders. Areas of focus include income level, education, geographic location, employment, health status, and future trends. Available from Howard University Research and Training Center, 2900 Van Ness St NW, Holy Cross Bldg, Ste 100, Washington, DC 20008.

Baca L, Bransford J. An appropriate education for handicapped children of limited English proficiency. Special education in America: its legal and governmental foundations series. The Council for Exceptional Children, 1982: 31 pages

One of a series of publications addressing the legal and governmental foundations of bilingual special education for children with handicaps. Also discussed are significant issues affecting the provision of bilingual special education. (EDRS: ED #224 265. To order, call 1-800-433-3742.)

Baca L. Policy options for insuring the delivery of an appropriate education to handicapped children who are of limited English proficiency. The Council for Exceptional Children, 1980: 58 pages

This article provides a historical overview of policy issues (litigation and legislation) involved in the provision of an appropriate education for bilingual children with handicaps. Then current practices and requirements are included. (EDRS:ED #199 963. To order, call 1-800-443-3742.)

From the National Center for Youth With Disabilities, Adolescent Health Program, University of Minnesota Hospital and Clinic, Minneapolis.

Towards a culturally competent system of care. CASSP Technical Assistance Center, Georgetown University Child Development Center, 3800 Reservoir Rd, NW, Washington, DC 20007, March 1989

This monograph is designed to assist states and communities in the provision of appropriate care to children from racially and culturally diverse groups who are severely emotionally disturbed. Included is a philosophical framework for cultural competence and practical suggestions for ways to improve service delivery.

***Coalition Q*. A publication of the Technical Assistance for Parent Programs (TAPP) Project, 1989 Spr/Sum;6(2 & 3)**

A special double issue containing proceedings of the Institute on Multicultural Issues, December 1987. Articles address general cultural issues and specific issues for Southeast Asian, Hispanic, and African-American cultures. Included is a list of national resources for children and families with special health needs from diverse cultures. Available from the Federation for Children With Special Needs, 95 Berkeley St, Boston, MA 02116, (617) 482-2915.

Cross TL. Services to minority populations: cultural competence continuum. *Focal Point*. Fall 1988;3:1–4

This article introduces a special issue of *Focal Point* devoted to sociocultural issues. The concept of cultural competence is defined and a continuum that illustrates responses to cultural differences by agencies, systems, and professionals is discussed. Possible responses include cultural destructiveness, cultural incapacity, cultural blindness, cultural precompetence, basic cultural competence, and advanced cultural competence. Available from Research and Training Center, Regional Research Institute for Human Services, Portland State University, PO Box 751, Portland, OR 97207-0751, (503) 725-4040.

Edson CH. Barriers to multiculturalism: historical perspectives on culture and character in American society. *Coalition Q*. Spr 1989;6(2&3):3–9

This article is a discussion of the roots of institutional racism and the ways that "scientific" theories have been used to influence our relationships with culturally different groups. The author suggests that cultural awareness requires that we examine ourselves and our own assumptions rather than merely developing an awareness of other cultures. Available from TAPP Project, Federation for Children With

Special Needs, 95 Berkeley St, Boston, MA 02116, (617) 482-2915.

Services to minority populations: what does it mean to be a culturally competent professional? *Focal Point*. Sum 1988;2(4)

This is the lead article in a special issue of *Focal Point* that addresses cross-cultural issues for professionals. Requirements for sound cross-cultural practice include awareness and acceptance of differences, self-awareness, understanding the dynamics of difference, knowledge of the clients' culture, and adapting skills to accommodate cultural differences. *Focal Point* is available from Research and Training Center, Regional Research Institute for Human Services, Portland State University, PO Box 751, Portland, OR 97207-0751, (503) 725-4040.

***News Digest*. National Information Center for Children and Youth With Disabilities (NICHCY), 1987, No. 9**

This edition of *News Digest* is focused on minority issues in special education. It provides information about trends in racial/ethnic composition in the United States and the effect of these trends on maternal and child health and special education. Suggestions are made as to ways to increase the numbers of special education teachers from minority groups and ways to improve relations between the school system and minority communities. To order, call NICHCY, 1-800-999-5599.

National Early Childhood Technical Assistance System. A bibliography of selected resources on cultural diversity for parents and professionals working with young children who have, or are at risk for, disabilities. 1989

Contains general information on cultural diversity and information on Asian/Pacific Islander, African-American, Hispanic, and Native American/Alaska Native cultural/ethnic populations. Cost is $6.00. Contact PACER Center, 4826 Chicago Ave S, Minneapolis, MN 55417-1055, (612) 827-2966.

Nidorf JF, Morgan MC. Cross cultural issues in adolescent medicine. *Prim Care*. Mar 1987; 14(1):69–82

Offers guidelines for physicians who are caring for adolescent patients with various cultural backgrounds. The physician should become aware of his or her own biases, develop a sensitivity to cultural variables that have an effect on the patients' perspective (use special interviewing techniques), consider a merger of traditional and Western interventions, view the family system and the adolescent's role within it, include the family in treatment plans while maintaining awareness of the adolescent as the patient, understand that efforts to change health behaviors may be complicated by cultural ritual and custom, be aware of the psychosocial component in the physician's role (be prepared to act as an advocate for the adolescent), and be aware that the use of an interpreter may affect confidentiality issues (special guidelines presented).

Pathfinder Resources. Improving state services for culturally diverse populations: focus on children with special health needs and their families

A report of a Maternal and Child Health Bureau work group for state directors of Children With Special Health Care Needs programs held during the national conference: "Cultural Perspectives in Service Delivery for Children and Families With Special Needs," May 1990, Washington, DC. The work group's purpose was to outline state-specific plans for service delivery to culturally diverse populations. Available from Pathfinder Resources, 2324 University Ave W, St Paul, MN 55114.

Phinney JS. Ethnic identity in adolescents and adults: review of research. *Psychol Bull*. Nov 1990;108(3):499–514

Seventy studies of ethnic and racial minority groups were reviewed. All were reported in journal articles published since 1972. This article discusses essential aspects of ethnic identity as a way of understanding the psychological importance of racial and ethnic identity and the important questions for researchers to address.

Portland State University, Research and Training Center on Family Support and Children's Mental Health. Issues in culturally competent service delivery: an annotated bibliography. 1990

Developed as part of the Minority Cultural Initiative Project, this bibliography addresses cultural issues for children and youth with emotional disabilities and their families. In addition to a general multicultural section, there are sections that are specific to African-American, Asian-American/Pacific Islander, Hispanic-Latino American, and Native American cultures. Order from Publications Coordinator, Research and Training Center, Regional Research Institute for Human Services, Portland State University, PO Box 751, Portland, OR 97207-0751, (503) 725-4040.

Randall DE. Strategies for working with culturally diverse communities and clients. Association for the Care of Children's Health, 7910 Woodmont Ave, Ste 300, Bethesda, MD 20814,1989:96

This manual for care providers explains cultural influences on beliefs, values, and actions. It presents guidelines for analyzing sociocultural factors in health and for working with culturally diverse populations. Exercises guide the reader in assessing his or her own cultural heritage.

Roberts RN. *Developing Culturally Competent Programs for Families of Children With Special Needs*. Georgetown University Child Development Center, 3800 Reservoir Rd, NW, Washington, DC 20007, Sept 1990

A monograph designed to assist in the development of culturally competent services to children and families. The concept of cultural competence is discussed in relation to community-based, family-centered care. Policy and practice issues are also included. Several model programs are described.

Roberts RN. Workbook for: *Developing Culturally Competent Programs for Families of Children With Special Needs.* 2nd ed, Sept 1990

Designed to be used in conjunction with the monograph *Developing Culturally Competent Programs for Families of Children With Special Needs.* This volume contains a series of self-study questions for program staff to use to develop culturally competent services. Available from Georgetown University Child Development Center, 3800 Reservoir Rd, NW, Washington, DC 20007, Sept 1990.

Wood PR, Zeltzer LK, Cox AD. Communicating with adolescents from culturally varied backgrounds: a model based on Mexican-American adolescents in South Texas. *Semin Adolesc Med.* Jun 1987;3(2):99–108

This article is a discussion of important issues for physicians who provide health care to adolescents of Hispanic descent. Included is a review of Mexican-American health and illness beliefs, the important role of the adolescent patient's family, and some culture-specific features for the physician to consider.

HALLMARKS OF A CULTURALLY DERIVED PROGRAM

Adapted from: Emily Vargas Adams, PhD. *Policy-Planning for Culturally Comprehensive Special Health Services.* Bureau of Maternal and Child Health, US Dept of Health and Human Services; February 1990. Also available from: CEDEN Family Resource Center, 1208 E 7th St, Austin, TX 78702, (512) 477-1130.

- Personnel of culturally derived programs recognize that cultural differences in child-rearing values and methods, as well as varying adaptations to family norms and interaction patterns of the majority culture, do not represent deficits in terms of family functioning and child development. Indeed, such differences frequently are considered to be intrinsic family strengths, as are many of the coping mechanisms of the parents.
- Culturally derived programs are highly participatory, involving the participants at all stages of program design, development, and implementation, including policymaking, community outreach, family identification, assessment, individualized family service planning, selection of program contents and methods, materials development and field testing, and program monitoring, evaluation, and feedback processes.
- Appropriate members of the local formal and informal leadership are involved in the design and development of the program from the outset, and they openly and tangibly give it their full support.
- Program objectives result from an in-depth community needs assessment and are regularly reviewed by community members to ensure their continued viability as well as to enable a flexible and rapid program response to new family and community challenges.
- Community outreach for the identification of children and parents needing services is conducted frequently, and families are personally invited in culturally appropriate ways to receive program services.
- Intake systems are designed to meet the expectations of potential program clients and to explain program services fully in appropriate ways. Screening and assessment instruments and forms are sensitive to family values and concerns, as well as adapted to meet the major prevailing needs of the families of the culture being served.
- Individual and family goals and objectives for treatment or service plans are listed, prioritized, and established by the parents, with the technical observations, assistance, and reinforcement of program staff. Staff members' roles are mainly informational and facilitative, rather than authoritative, since only by means of familial commitment to learning objectives will they ultimately be achieved. Families periodically assess the achievement of their own goals.
- Family goals must be incorporated into each family's treatment or service plan in order for it to be successful. Doing this permits intracultural variability to be handled on a case-by-case basis and helps to reduce the possibility of intrafamilial cultural conflict which can occur when values of the majority culture are used by young families to the regret of the older generation. Also, differing strategies can be used to assist specific family members or types of families as needed.
- Emphasis is placed upon maintaining and/or improving the self-esteem, cultural identification, and goal-setting ability of each family, with special attention to assisting the family to achieve and maintain self-sufficiency within the context of the larger society.
- Parent-child interaction patterns chosen by program personnel and parents to be enhanced and taught—especially to adolescent parents—must fit the ideal parenting values and behaviors of the culture. This "cultural fit" is essential for promoting positive behaviors and assisting the children to develop those abilities which will lead to successful school achievement. Of course, care must be taken to avoid promoting any traditional patterns of parenting which could become injurious to children in US community settings.
- In addition to working with the parents, all immediate caregivers and members of the extended family should be encouraged to participate actively in the program. Thus, the entire teaching/learning context of the child should be the subject of a culturally derived program.
- Criteria for staff selection should be explicitly stated. At least one member of the service team assisting the family should be as culturally continuous with the family as possible, and all team members should receive preservice and in-service training tailored to ensure culturally appropriate service provision.
- Both the educational materials and media, as well as the program's evaluation and monitoring instruments, must be derived from the local culture(s) (or a similar cultural setting) and extensively field-tested for appropriateness and communicability in terms of their illustrations or

drawings, the symbols selected for use, the readability of written text, and their methods of use.

- In addition, educational methods must be congruent with those of the culture. Usually, special emphasis should be placed upon the use of demonstrations, immediately followed by active practice.
- Home outreach usually is essential to establish rapport, encourage active participation in all phases of program services, and maximize achieving the goals of the individualized family service plan.
- Family advocacy must include a component for assisting parents to access, utilize appropriately, and retain essential health and human services.
- Typical family celebrations and symbolism should be incorporated within program services, with family representatives taking a leading role in the preparation of events, foods, and materials. However, the observance of such celebrations and the casual use of symbols do not ensure that the rest of the program will be acceptable to the people of the specific cultural group to be served.
- The program must be continuously evaluated in order to ensure its evolutionary development within the changing community setting.

BIBLIOGRAPHIC MATERIALS

EDUCATION

Almanza HP, Mosley WJ. Curriculum adaptations and modifications for culturally diverse handicapped children. *Except Child.* May 1980;46(8):608–614

Discussion of instructional planning and curriculum development for special education students from various racial or ethnic backgrounds. Included are issues to be considered, such as curriculum materials, values, individual learning styles, and strategies for providing a multicultural curriculum in special education.

Aloia GF, Maxwell JA, Aloia SD. Influence of a child's race and the EMR label on initial impressions of regular-classroom teachers. *Am J Ment Defic.* May 1981;85(6):619–623

The purpose of this study was to investigate the influence of race and the educable mental retardation (EMR) label by comparing initial impressions of attractiveness, intelligence, and behavior when teachers (n = 99) were shown photographs of students who were African-American, Mexican-American, and white. Data indicate that the race of the student significantly influenced the teachers' overall initial expectations and that the EMR label significantly reduced teacher's initial impressions of intellectual potential. The EMR label also tended to have a less negative effect on impressions of behavior of white students compared to African-American or Mexican-American students.

Bice TR, Halpin G, Halpin G. A comparison of the cognitive styles of typical and mildly retarded children with educational recommendations. *Educ Train Ment Retard.* Jun 1986;21(2):93–97

The authors compared the cognitive styles of African-American and white children (aged 8–13 years) who are mildly mentally retarded. Data indicate that older white children without mental retardation are the most field independent, while younger African-American children with mental retardation are the most field dependent. Recommendations for modifying learning environments to account for differences in cognitive style are included.

Cardoza D, Rueda R. Educational and occupational outcomes of Hispanic learning-disabled high school students. *J Spec Educ.* Spr 1986;20(1):111–126

This study evaluates the course-taking behavior, educational aspirations, and educational outcomes of Hispanic learning-disabled, non-Hispanic learning-disabled, and non–learning-disabled high school sophomores and seniors. Results showed a significant difference in educational aspirations and outcomes between the learning-disabled and non–learning-disabled groups, but no significant results were found between the Hispanic learning-disabled and non-Hispanic learning-disabled groups.

Cegelka PT, MacDonald M, Gaeta R. Bilingual special education. *Teach Except Child.* Fall 1987;20(1):48–50

A description of two bilingual special education programs which serve as demonstration sites in the state of California. Southwest High School and Paramount Elementary School utilize the "seven promising practices" recommended for schools that deliver special education services to bilingual students.

Chess S, Fernandez P, Cohen P, et al. Selective bias in educational mainstreaming of deaf, intellectually normal adolescents. *J Am Acad Child Psychiatry.* Mar 1984;23(2):198–202

Comparison of two groups of 83 profoundly deaf adolescents with congenital rubella citing ethnicity and socioeconomic status as primary determinants of school placement; case examples.

Chinn PC. *Education of Culturally and Linguistically Different Exceptional Children.* The Council for Exceptional Children, 1920 Association Dr, Reston, VA 22091, 1984:131 pages

This monograph contains five papers on the education of culturally and linguistically diverse students with disabilities. Topics include demographics, testing and evaluation, cognitive development, curriculum development, and teacher education. (EDRS: ED #256 103. To order, call 1-800-443-3742.)

Cohen OP, Fischgrund JE, Redding R. Deaf children from ethnic, linguistic and racial minority backgrounds: an overview. *Am Ann Deaf.* Apr 1990;135(2):67–73

This article reports demographic data showing the numbers and distribution of minority students with hearing impairments and presents a discussion of the failure of schools and school personnel to consider the ethnic, cultural, religious, and racial heritage of deaf students. Included is a list of recommendations from the first national conference (March 1989) on the needs of black and Hispanic deaf children held at Gallaudet University.

Dodd JM, Hermanson M, Nelson JR, et al. Tribal college faculty willingness to provide accommodations to students with learning disabilities. ***J Am Indian Educ.*** **Oct 1990;30(1):8–16**

Faculty members at the Salish Kootenai College, a community college on the Flathead Reservation in Montana, were studied to determine the instructional accommodations they were willing to provide to students with learning disabilities. There was agreement about the provision of some accommodations and indecision about others. American Indian students with learning disabilities need to utilize self-advocacy skills to ensure their access to the opportunities other students with learning disabilities have.

Duran E. Teaching functional reading in context to severely retarded and severly retarded autistic adolescents of limited English proficiency. ***Adolescence.*** **Sum 1985;20 (78):433–439**

Describes specific ways to teach functional reading in context to adolescents with limited English proficiency who also have autism or severe mental retardation. By combining functional or essential reading with meaningful activities, instructors can effectively teach reading to adolescents with autism or severe mental retardation and thereby enable students with limited English proficiency to become more independent.

Duran E. ***Teaching the Moderately and Severely Handicapped Student and Autistic Adolescent: With Particular Attention to Bilingual Special Education.*** **Springfield, IL: Charles C Thomas; 1988:225**

This text focuses on identifying needs and offering options for professional intervention. Topics include language intervention strategies, vocational training, transitions, postsecondary programs, students with autism or multiple handicaps (especially those which include sensory impairment), parent and family issues, Hispanic issues, and issues related to the culturally and linguistically different student.

Fradd SH, Correa VI. Hispanic students at risk: do we abdicate or advocate? ***Except Child.*** **Oct 1989;56(2):105–110**

The number of students with limited English proficiency as well as disabilities is increasing, and appropriate services are needed to properly integrate these students. A lack of awareness of this need as well as a lack of adequate training in cross-cultural communication represents the major obstacles to the provision of service to these students. Transdisciplinary teaming is suggested as an approach to begin meeting their needs.

Garcia SB, Yates JR. Policy issues associated with serving bilingual exceptional children. ***J Read Writ Learn Disabil Int.*** **1986;2(2):123–137**

Discusses policy issues related to serving the learning needs of bilingual minority students with disabilities. A review of research indicates that currently there are problems and difficulties in the delivery of services to bilingual students with disabilities. Recommendations are given for identification of students with learning disabilities, program development in public schools, and professional development of teaching staff.

Gregory JF, Shanahan T, Walberg H. Learning disabled 10th graders in mainstreamed settings: a descriptive analysis. ***Remedial Spec Educ.*** **Jul 1985;6(4):25–33**

A descriptive analysis of 10th-grade students in the United States with learning disabilities. Data indicate that the sample of students with learning disabilities was older, had a disproportionate number of African-Americans and Hispanics, and had more secondary handicapping conditions than did the sample of students without learning disabilities. The students with learning disabilities also had lower measures of individual psychology, academic achievement, and school-related problems.

Hilliard AG. Cultural diversity and special education. ***Except Child.*** **May 1980;46(8):584–588**

Discussion of how special education succeeds and fails with a culturally diverse student population. The overrepresentation of children who are African-American or Hispanic in classes for students with educable mental retardation raises serious issues regarding the diagnosis of mental retardation. The author stresses the importance of considering the student's cultural background in both diagnosis and education.

Horan KT. Effects of head injury on the educational and vocational potential of American Indians. ***Rural Spec Educ Q.*** **1986;8(1):19–22**

Part of a special, theme issue addressing provision of services to cross-cultural populations. This article looks at causes of head injury among American Indians living on reservations. It offers safety precautions and also activities for teachers to utilize with American Indian students who have sustained head injuries.

Luetke-Stahlman B. Using bilingual instructional models in teaching hearing-impaired students. ***Am Ann Deaf.*** **Dec 1983;128(7):873–877**

Presents advantages and disadvantages of various instructional models for bilingual students with hearing impairments. Rather than immerse students in the dominant language of society, many schools are using bilingual instructional models for students with hearing impairment that involve a half-day of each language, a bilingual teacher, or a slow transition from the native language to the dominant language.

MacMillan DL. 'New' EMRs. Chapter One. ***Best Practices in Mental Disabilities.*** **Vol 2. Robinson GA; EDRS, 1988**

Examines changes in the population of students categorized as educable mentally retarded (EMR). Despite the reduction in the number of children classified as EMR, ethnic minorities such as African-Americans and Hispanics continue to be disproportionally classified as EMR. Philosophical questions concerning appropriate educational programs for the

"new" EMR students are addressed. (EDRS: ED #304 829. To order, call 1-800-443-3742.)

MacMillan DL, Hendrick IG, Watkins AV. Impact of Diana, Larry P, and PL 94-142 on minority students. ***Except Child.*** **Feb 1988;54(5):426–432**

This article examines the effect on minority students of changes in identification and programming due to PL 94-142 for students with educable mental retardation (EMR). The discussion includes the possibility of racial isolation in EMR programs, reverse racism in EMR identification, the needs of children with IQs of 70–85, and the concerns of marginally achieving minority students in regular education.

Miramontes OB. Organizing for effective paraprofessional services in special education: a Multilingual/ Multiethnic Instructional Service team model. ***Remedial Spec Educ.*** **Jan/Feb 1990;12(1):29–36,47**

This article is a discussion of the use of bilingual-bicultural paraprofessionals as a way for school districts to meet the needs of culturally and linguistically diverse students needing special education services. The model presented is the Multilingual/ Multiethnic Instructional Service (MMIS) team composed of trained paraprofessionals and a certified special education teacher serving as a team resource specialist. The team allows for consideration of the students' language and culture when assessing special education needs and designing an appropriate instructional program.

Murray-Seegert C. ***Nasty Girls, Thugs and Humans Like Us.*** **Baltimore, MD: Paul H. Brookes; 1989:198**

Using an ethnographic approach in a troubled urban high school, the author studied 30 students with disabilities and 32 nondisabled students (many of whom were from racial minority groups) in order to understand the process of integration. The problems with and benefits of integration are explored for students with and without disabilities in this insightful book.

Ortiz AA. Language and curriculum development for exceptional bilingual children. In: Chinn PC. ***Education of Culturally and Linguistically Different Exceptional Children.*** **The Council for Exceptional Children, 1920 Association Dr, Reston, VA 22091, 1984:25 pages**

A review of the literature associated with language and curriculum development for bilingual children with disabilities. Included are several successful models for teaching bilingual children with disabilities and recommendations for the development of policies that ensure appropriate services for all bilingual students with disabilities. (EDRS: ED #256 107. To order, call 1-800-443-3742.)

Poplin MS, Wright P. The concept of cultural pluralism: issues in special education. ***Learn Disabil Q.*** **Fall 1983;6 (4):367–371**

This article serves as an introduction to an entire issue of *Learning Disabilities Quarterly* which is devoted to exploring the issue of cultural pluralism as related to special education. Topics include bilingual education, assessment, discrimination, multicultural instruction, and ways to deal with cultural differences in special education.

Rueda R. Cognitive development and learning in mildly handicapped bilingual children. In: Chinn PC. ***Education of Culturally and Linguistically Different Exceptional Children.*** **The Council for Exceptional Children, 1920 Association Dr, Reston, VA 22091, 1984:15 pages**

A review of the literature on the relationship between language and cognition in bilingual children who have mild mental retardation. Research results suggest that in children with mild mental retardation, highly proficient bilingual students tend to have a cognitive advantage over both low-proficiency bilingual students and monolingual children. The author also examines the cognitive and interactional factors that affect language acquisition and presents a case for an interactive approach to learning in bilingual children who have mental retardation. (EDRS: ED #256 106. To order, call 1-800-443-3742.)

Saunders M. Cultural diversity in special education. ***Spec Educ Forward Trends.*** **Mar 1981;8(1):15–17**

A discussion of problems and barriers to multicultural education in the special education system. Topics include assessment, multicultural curriculum, cultural identity, communication difficulties, race relations, and ways in which to remove the barriers to multicultural education.

Slade JC, Conloey CW. Multicultural experiences for special educators. ***Teach Except Child.*** **Fall 1989;60–64**

Describes an ethnic education project that sensitizes college students who are preparing to teach multicultural children with handicaps. Students develop an awareness of various ethnic and cultural groups by reading fiction and nonfiction, viewing movies and videotapes, hearing presentations by ethnic group members, and developing case histories of multiethnic group families having a child with a disability.

Stewart DA, Benson G. Dual cultural negligence: the education of black deaf children. ***J Multicultural Counsel Dev.*** **Jul 1988;16(3):98–109**

According to the authors, hearing loss and ethnicity constitute a dual educational disadvantage for students who are black and deaf. School systems must be aware of the existence of a deaf culture and also the importance of the students' cultural heritage. The article includes a list of recommendations to be considered when developing an educational program for students who are black and deaf.

Wyche LG. The ***Tenth Annual Report to Congress*****: taking a significant step in the right direction.** ***Except Child.*** **Sep 1989;56(1):14–16**

The ***Tenth Annual Report to Congress*** on PL 94-142 is critically analyzed. For the most part, it appears that the implementation of PL 94-142 has resulted in positive benefits for white, socioeconomically advantaged children. Among ethnic minority children, especially African-American children of low socioeco-

nomic status, the benefits are significantly less. A primary analysis of dropout rate differences among racial populations is proposed.

ASSESSMENT AND TESTING

Bailey DB, Harbin GL. Nondiscriminatory evaluation. *Except Child.* May 1980;46(8):590–596

Review of literature regarding nondiscriminatory evaluation, and discussion of issues related to cultural bias in the diagnosis of special education students. The current status of bias in educational decision-making is presented along with strategies for removing discrimination from the evaluation process.

Kayser H. Speech and language assessment of Spanish-English speaking children. *Lang Speech Hear Serv Sch.* Jul 1989;20(3):226–244

Presents a framework and provides suggestions concerning the diagnosis of speech and language disorders in Spanish-English speaking students. To ensure accurate diagnosis, the author suggests that professionals consider observations, interviews, questionnaires, nonbiased test instruments, and the cultural/linguistic background of the child and family.

Nuttall EV, Landurand PM, Goldman P. A critical look at testing and evaluation from a cross-cultural perspective. In: Chinn PC. *Education of Culturally and Linguistically Different Exceptional Children.* The Council for Exceptional Children, 1920 Association Dr, Reston, VA 22091, 1984:22 pages

This review of testing and evaluation discusses common problems in distinguishing a disability from a cultural difference, legal issues in special education assessment, uses and misuses of assessment instruments, and methods of nondiscriminatory assessment. Recommendations are made for development of nondiscriminatory policies in special education assessment. (EDRS: ED #256 105. To order, call 1-800-443-3742.)

Wolk S. Biasing influence on test level assignments for hearing impaired students. *Except Child.* Oct 1985;52(2):161–169

This study examined the effects of race, gender, and degree of hearing impairment upon teachers' judgments of academic potential in a sample of 1329 students (aged 12–19 years) with hearing impairments. Results suggest that white students, female students, and students with less severe hearing impairments were disproportionately assigned by their teachers to more advanced test levels.

EMPLOYMENT

Cantor JA. Evaluation of BVT programs: a systematic model. *J Vocational Spec Needs Educ.* Fall 1987;10(1):9–12

Presentation of a bilingual vocational training (BVT) evaluation model: analysis, design, development, implementation, and evaluation. Input, process, and output elements are identified.

Duran E. Teaching vocational, functional language and reading skills to the adolescent Hispanic severely handicapped. EDRS, Nov 1982:17 pages

Discusses vocational and language skill development of Hispanic adolescents with severe mental retardation and/or autism. Through bilingual instruction and a variety of instructional activities, Hispanic adolescents with severe handicaps are trained in daily living skills in order to promote independent life. (EDRS: ED #228 759. To order, call 1-800-443-3742.)

Fair GW. Career education and minority handicapped students. *Career Dev Except Individuals.* Spr 1980;3(1):3–11

Discussion of issues related to race and career education including attitudes, accessibility, teacher preparation, adaptation of the instructural process, and testing and vocational assessment.

Fair GW, Sullivan AR. Career opportunities for culturally diverse handicapped youth. *Except Child.* May 1980;46(8):626–631

An overview of the employment situation for culturally diverse youth with disabilities and implications for career and vocational education. Included is a discussion of the barriers to effective educational and employment opportunities and recommendations to provide successful career development for culturally diverse youth with disabilities.

O'Connell JC, Johnson MJ. *Native American rehabilitation: A Bibliographic Series.* Native American Research and Training Center, Northern Arizona University, Box 5630, Flagstaff, AZ 86011, 1986

This series consists of seven annotated bibliographies on seven different subject areas: assessment, rehabilitation, special education, family, mental health, health care, and medically related disability issues. All attempt to present a comprehensive summary of the existing literature as it relates to the population of Native Americans with disabilities.

Plata M, Jones P. Bilingual vocational education for handicapped students. *Except Child.* Apr 1982;48(6):538–540

Describes a coordinated approach to providing bilingual vocational training to limited or non-English-speaking handicapped students (LONESHS). The team consists of the vocational teacher, the special education teacher, and the bilingual teacher; roles and functions are outlined. All must work together to counteract the problems LONESHS often encounter in the public school system.

Walker S. Building bridges to employment. *OSERS News in Print.* Spr 1991;III(4):6–9

This article highlights innovative mentorship and transition models that have been developed to prepare minority youth with disabilities for future employment. Included are The Collaborative Model; the Future Assets Student Talent (FAST) Program; The Howard University Bridges to Leadership 2000 Youth Training Program; and The Systems Success Program. This newsletter is available from the Office

of Special Education and Rehabilitation Services; Switzer Building, Room 3129;330 "C" St SW, Washington, DC 20202-2524, (202) 732-1723.

HEALTH

Adams J. The assessment of pain related to invasive procedures in Anglo and Hispanic children with cancer. *J Assoc Pediatr Oncol Nurses.* 1988;5(1–2):31

This study analyzed the reliability and validity of methods used to assess the pain of 78 Anglo and Hispanic children with cancer. Results show a high reliability between observational and self-report methods and a significantly higher anxiety score for Hispanic parents.

Berlin IN. Prevention of emotional problems among Native-American children: overview of developmental issues. *Annu Prog Child Psychiatry Child Dev.* 1983:320–333

Describes various social and developmental issues in the prevention and identification of emotional problems and developmental disabilities in Native-American children.

Delamater AM, Albrecht DR, Postellon DC, et al. Racial differences in metabolic control of children and adolescents with type 1 diabetes mellitus. *Diabetes Care.* Jan 1991;14(1):20–25

This study examined whether there were any racial differences in metabolic control of children and adolescents with type 1 diabetes mellitus. Adolescents, in general, were in poorer metabolic control than children, and black children and adolescents were found to be in poorer control than white children and adolescents. Areas suggested for further study include the effects of socioeconomic, psychological, behavioral, and biological factors.

Delmar-McClure N. When organs match and health beliefs don't: bioethical challenges. *J Adolesc Health Care.* May 1985;6(3):233–237

This paper examines the bioethical problem of organ transplantation in patients whose socioethnic health care beliefs are not addressed pretransplant. Case studies of two Hispanic adolescents whose organ transplants failed are presented to highlight the need for a cognitive-behavioral therapeutic approach that addresses the beliefs of the patient in order to ensure successful transplant surgery.

***Gathering and Sharing: An Exploratory Study of Service Delivery to Emotionally Handicapped Indian Children.* Research and Training Center, Regional Research Institute for Human Services, Portland State University, PO Box 751, Portland, OR 97207-0751, (503) 725-4040**

Findings from Idaho, Oregon, and Washington covering current services, successes, service delivery barriers, exemplary programs and innovations. $4.50 per copy. Available from the publisher.

Hanson CL, Henggeler SW, and Burghen GA. Race and sex differences in metabolic control of adolescents with IDDM: a function of psychosocial variables? *Diabetes Care.* May 1987;10(3):313–318

This study matched African-American adolescent participants with white adolescent participants, according to sex, on important demographic and biological variables. In so doing, the researchers attempted to isolate differences in metabolic control which might be attributable to race and/or sex. African-American adolescent girls were found to exhibit significantly poorer metabolic control than any of the other race-by-sex groups. Implications for morbidity and mortality are discussed. No significant differences between groups were found on psychosocial measures.

Katz-Leavy J, Lourie IS, Kaufmann R. Meeting the mental health needs of severely emotionally disturbed minority children and adolescents: A national perspective. *Child Today.* 1987;16(5):10–14

This article describes CASSP (Child and Adolescent Service System Program), a program of the National Institute of Mental Health to improve mental health services to culturally diverse emotionally disturbed children, adolescents, and their families. Technical assistance is provided to states so that programs and services will be culturally relevant. Issues and factors that should be considered are listed. Several states' demonstration projects are described.

Pfefferbaum B, Adams J, Aceves J. The influence of culture on pain in Anglo and Hispanic children with cancer. *J Am Acad Child Adolesc Psychiatry.* Jul 1990;29(4):642–647

Studied while undergoing painful procedures for the treatment of cancer, the 35 Anglo and 43 Hispanic children (3–15 years of age) had similar behavioral responses to pain; for both groups, there was an inverse relationship between age and distress. When the parents were studied, however, it was found that Hispanic parents reported higher anxiety levels than the Anglo parents.

Price JH, Desmond SM, Wallace M, et al. Differences in black and white adolescents' perceptions about cancer. *J Sch Health.* Feb 1988;58(2):66–70

Survey of cancer knowledge, attitudes, and beliefs among 573 African-American and 297 white secondary school students. Nine significant differences were found between these two groups on cancer knowledge (etiology, warning signs, and prevention techniques). Further significant differences were found on the Health Belief Model subscales: cues to action, perceived susceptibility, perceived severity, perceived barriers, perceived benefits, and interpersonal relationships. African-Americans and whites received cancer information from the same sources, with the exception of books, which was reported less frequently by whites.

Seltzer A. Acculturation and mental disorder in the Inuit. *Can J Psychiatry.* Mar 1980;25(2):173–181

Case studies highlight the mental and emotional disorders that may develop in adolescent Eskimos who are experiencing the stress of cultural change. As the traditional Eskimo culture is assimilated with Western society, the young adult male Eskimo is especially susceptible to feelings of anxiety, powerless-

ness, low self-esteem, and negative self-image that may lead to increased incidence of mental disorder.

VanDenBerg J, Minton BA. Alaska native youth: a new approach to serving emotionally disturbed children and youth. *Child Today.* Sep 1987;16(5):15–18

A description of CASSP (Child and Adolescent Service System Program) projects for Alaska's native youth. Mental health services are being planned and provided with an understanding of cultural differences. Village control and design of program is being used to address the problems of native youth who are being affected by conflicting cultural values.

Williams CL, Westermeyer J. Psychiatric problems among adolescent Southeast Asian refugees. A descriptive study. *J Nerv Ment Dis.* Feb 1983;171(2):79–85

An investigation of Southeast Asian adolescent psychiatric patients that includes patient complaints and problems, diagnostic categories, demographic characteristics, and cultural aspects of treatment. Authors emphasize the need for the therapist to be aware of differences in cultural norms.

Wissow LS, Gittelsohn AM, Szklo M. et al. Poverty, race, and hospitalization for childhood asthma. *Am J Public Health.* Jul 1988;78(7):777–782

Hospital records of 9041 children (aged 1–19) were used to determine whether race and poverty are correlated with rate of hospitalization for childhood asthma. Data indicate that, overall, African-American children had higher rates of hospitalization for asthma than white children. When the data were adjusted for socioeconomic differences, African-American and white children had nearly equal rates of hospitalization for asthma.

Zeltzer LK, LeBaron S. Fantasy in children and adolescents with chronic illness. *J Dev Behav Pediatr.* Jun 1986;7(3):195–198

Explores the use of fantasy to control pain, communicate, and cope with the stress of chronic illness and medical treatment. The authors distinguish between imagery (consisting of pictures) and fantasy (consisting of pictures accompanied by stories). Specific cases of adolescents are used to illustrate. Cultural differences in the interpretations of fantasies are addressed.

EPIDEMIOLOGY

Akinsola HA, Fryers T. A comparison of patterns of disability in severely mentally handicapped children of different ethnic origins. *Psychol Med.* Feb 1986;16(1):127–133

School records were reviewed and teachers were interviewed to assess the level of disability of each child (n = 326; 5–19 years). More severe disabilities were found among children of non-European descent. Boys experienced more severe problems. Possible etiologic factors are discussed.

Dew N. The exceptional bilingual child: Demography. In: Chinn PC. *Education of Culturally and Linguistically Different Exceptional Children.* The Council for Exceptional Children, 1920 Association Dr, Reston, VA, 22091, 1984:44 pages

This descriptive study documents the prevalence of exceptional bilingual children by handicapping condition, analyzes trends and patterns in the data, and makes recommendations for the delivery of services. (EDRS: ED #256 104. To order, call 1-800-443-3742.)

Fischgrund JE, Cohen OP, Clarkson RL. Hearing-impaired children in black and Hispanic families. *Volta Rev.* Sep 1987;89(5):59–67

This paper presents basic sociocultural information on African-American and Hispanic families raising children with hearing impairments. Included are demographic data, discussions of cultural differences, and implications for professionals who serve minority families and children with hearing impairments.

McShane D. An analysis of mental health research with American Indian youth. *J Adolesc.* Jun 1988;11(2):87–116

A review of the literature on the mental health of American Indian youth. Included is research on otitis media, fetal alcohol syndrome, abuse and neglect, psychiatric epidemiology, neurosensory disorders, developmental disabilities, conduct disorders, drug and alcohol use, self-concept, suicide and depression, and school-related problems. Limitations of the current research and the need for more research related to the mental health of American Indian youth is highlighted.

Rosenstein BJ, Perman JA, Kramer SS. Peptic ulcer disease in cystic fibrosis: an unusual occurrence in black adolescents (letter). *AJDC.* Oct 1986;140(10):966–969

The authors report the unusual occurrence of peptic ulcer disease in three African-American adolescents with cystic fibrosis. A review of the literature regarding peptic ulcer disease and cystic fibrosis indicates that concurrence of the two diseases is relatively rare in adolescents who are African-American compared to adolescents who are white.

Spitz MR, Sider JG, Johnson CC, et al. Ethnic patterns of Hodgkin's disease incidence among children and adolescents in the United States. *J Natl Cancer Inst.* Feb 1986;76 (2):235–239

The purpose of this article is to characterize the incidence of Hodgkin's disease according to age, race, and gender in childhood and early adolescence. Results indicate that incidence rates increase with age, that incidence rates appear to be higher among ethnic groups with lower socioeconomic status, and that there is no significant difference between incidence rates for males and females.

Stewart JM. Multidimensional scaling analysis of communicative disorders by race and sex in a mid-south public school system. ***J Commun Disord.*** **Nov 1981;14(6):467–483**

This study presents demographic data (according to race and gender) on the prevalence of communicative disorders in the Nashville public schools. Results indicate that when the racial balance within the schools is considered, the prevalence of communication disorders does not vary significantly by race.

US Department of Education; Office of Special Education and Rehabilitative Services; Rehabilitative Services Administration. ***A Study of the Special Problems and Needs of American Indians With Handicaps Both on and off the Reservation.*** **Northern Arizona University, Native American Research and Training Center, Box 5630, Flagstaff, AZ 86011, 1987:341**

Consists of three volumes: Executive Summary, Individual Reports, and Appendices. The study sought answers to three major questions: What is the prevalence of disability among American Indians? What are the special problems of American Indians related to vocational rehabilitation? What is the nature and extent of cooperative efforts among programs conducted under the Rehabilitation Act of 1973, as amended by Public Law 99-506?

PARENTS

Flynt SW, Wood TA. Stress and coping of mothers of children with moderate mental retardation. ***Am J Ment Retard.*** **Nov. 1989;94(3):278–283**

The purpose of this study was to investigate the perceived family stress levels and coping behaviors of mothers with children (n = 111; 6–21 years) who are moderately mentally retarded. Findings suggest that in families with children who are mentally retarded, mothers who are African-American and mothers who are older reported significantly less family stress levels than mothers who are white and mothers who are younger.

Jenkins JH. Ethnopsychiatric interpretations of schizophrenic illness: the problem of nervios within Mexican-American families. ***Cult Med Psychiatry.*** **Sep 1988;12(3):301–329**

This article examines the nature and meaning of the word "nervios" (nerves) as used by Mexican-American families to understand schizophrenia in a relative. Results indicate that the term is used by Mexican-American families to describe a broad range of mental illnesses and that this cultural folk label may help family members reduce the stigma associated with mental illness, strengthen family relationships, and mediate the course and outcome of schizophrenia.

Malach RS, Segel N. Perspectives on health care delivery systems for American Indian families. ***Child Health Care.*** **1990;19(4):219–228**

American Indian families with health-impaired children and health care providers were interviewed to assess factors that facilitate or inhibit use of health care services and ways to improve services. Findings indicated the importance of emotional support, respect, and health communication, including the use of interpreters, easier to understand explanations, and an understanding of cross-cultural communication-interaction styles. Services should be culturally appropriate. Policies and procedures are often restrictive or confusing. Providers wanted more involvement by the tribal government. Both groups indicated a need for improved services for children with special health care needs.

Marion RL. Communicating with parents of culturally diverse exceptional children. ***Except Child.*** **May 1980;46(8):616–623**

Presentation of the reactions, concerns, and needs of parents with children who have disabilities and are from racial or ethnic minority groups. Suggestions are made regarding ways to improve communication between educators and parents. Emphasis is placed upon increased understanding and awareness of cultural differences.

Smith MJ, Ryan AS. Chinese-American families of children with developmental disabilities: an exploratory study of reactions to service providers. ***Ment Retard.*** **Dec 1987;25(6):345–350**

This exploratory study was designed to uncover some of the problems that may occur when social service agents do not speak the language of their clients. Interviews with Chinese parents (n = 59) of children who are developmentally disabled showed that language barriers prevented a full understanding of the diagnosis and service delivery plan. Other cultural issues are also discussed.

PSYCHOSOCIAL

Cowardin NW. Adolescent characteristics associated with acceptance of handicapped peers. ***Adolescence.*** **Win 1986;XXI(84):931–940**

This study of 41 non-disabled adolescents' attitudes toward their peers with disabilities (mean age = 15.8 years) compared results of sociometric tests with student records. Girls and Mexican-Americans were found to be more accepting of disabilities. Moral development, popularity, chronological age, and school achievement were all found to be positively correlated with acceptance. Socioeconomic status, physical ability, and length of association did not prove predictive.

Gregory JF, Shanahan T, Walberg H. A descriptive analysis of high school seniors with speech disabilities. ***J Commun Disord.*** **Aug 1985;18(4):295–304**

This descriptive study compared adolescents with speech disabilities to peers without disabilities. Results indicate that Hispanic and Asian-Americans tend to be significantly overrepresented in the sample with speech disabilities and that adolescents with speech disabilities tend to be at a disadvantage regarding achievement, self-image, motivation, and career aspirations.

Hagborg WJ. A sociometric investigation of sex and race peer preferences among deaf adolescents. *Am Ann Deaf.* Oct 1989;134(4):265–267

Investigated sex and race peer preferences among 144 adolescents with deafness. Results indicate there is a peer preference for females by both male and female adolescents with deafness, and there is a same-race preference among white adolescents with deafness. Also, the sex and race preferences of these adolescents correspond to the sex and race preferences of hearing youth.

Henderson RW. Social and emotional needs of culturally diverse children. *Except Child.* May 1980;46(8):598–605

Discussion of cultural diversity and stereotypes, a path model for children at risk, perceptions of personal efficacy (eg, locus of control, attribution theory, learned helplessness), and facilitating environments and therapeutic approaches.

Jenkins AE, Amos OC, Graham GT. Do black and white college students with disabilities view their worlds differently? *J Rehabil.* Jul 1988;54(3):71–76

Findings indicate that the two groups do not view their worlds in significantly different ways. Responses to questions about family relationships, human services, and feelings about self were very similar.

Jenkins AE, Amos OC. Being black and disabled: a pilot study. *J Rehabil.* Apr 1983;49(2):54–60

Sixty-nine African-American students with and without disabilities were compared on a number of psychosocial variables. Few differences were found between the two groups, with one exception being that students with disabilities found early school experiences to be relatively less satisfying than did students without disabilities.

Levy JE. Psychological and social problems of epileptic children in four southwestern Indian tribes. *J Community Psychol.* Jul 1987;15(3):307–315

The author compared social and emotional problems in 88 Pueblo and Navajo children (6–19 years of age) with seizure disorders. Results indicate that Navajo children with seizure disorders have significantly more social and emotional problems than Pueblo children, and these problems tend to start earlier in life. The author hypothesizes that differences in social and emotional problems may be due to differences in beliefs about seizure disorders, parental reactions to children with seizure disorders, migration rates, and access to health services.

Loeb R, Sarigiani P. The impact of hearing impairment on self-perceptions of children. *Volta Rev.* Feb 1986;88(2):89–100

The authors compared personality differences in 250 African-American and white students (aged 8–15 years) with varying degrees of hearing impairments and visual impairments. Students with hearing impairments were found to have lower self-esteem and more problems in peer and family relations. Contrary to the general population, African-American students with hearing impairments were found to have a more internal locus of control, while white students with hearing impairments were found to have an external locus of control.

Radencich MC. Literature for minority handicapped students. *Reading Res Instruction.* Sum 1986;25(4):288–294

This article cites literature that is particularly relevant to students who are from minority groups and who are also disabled. The collection of materials addresses needs specifically pertinent to this group of youth. The books are targeted for individuals with handicaps and their families, peers, and teachers.

Zeltzer LK, LeBaron S. Does ethnicity constitute a risk factor in the psychological distress of adolescents with cancer? *J Adolesc Health Care.* Jan 1985;6(1):8–11

This study was done to determine whether ethnicity (Hispanic vs Anglo) constituted a risk factor in the psychological distress of adolescents with cancer. Ethnic comparisons were made on four psychological measures administered to 54 adolescents with cancer (mean age = 13.6 years). The researchers concluded that ethnicity per se was not a risk factor to adolescents with cancer.